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**Northeast and Caribbean Region**

**Region II**

# **REPORT ON PROCEEDINGS**

## **HHS COMMUNITY MEETING ON HIV/AIDS:**

**CONFRONTING THE SECOND GENERATION OF THE EPIDEMIC**

**Brooklyn, New York**

**January 14, 1999**

**Conference planning provided by:**

Regional Director's Work Group on HIV/AIDS  
U.S. Department of Health and Human Services,  
Northeast and Caribbean Region, Region II

**Conference logistics provided by:**

U.S. Department of Health and Human Services,  
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**Northeast and Caribbean Region**  
**HHS Community Meeting on HIV and AIDS:**  
**Confronting the Second Generation of the Epidemic**

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**Northeast and Caribbean Region**  
**HHS Community Meeting on HIV and AIDS:**  
**Confronting the Second Generation of the Epidemic**

## **Executive Summary**

The Department of Health and Human Services (HHS), Northeast and Caribbean Region Community Meeting on HIV/AIDS convened in Brooklyn, New York on January 14, 1999 entitled "Confronting the Second Generation of the Epidemic" is an example of how we must continue to work at the partnership between government, the community, and the private sector to successfully address the barriers we face in our continued fight against HIV/AIDS. At the meeting we examined the successes and challenges that we currently face in creating policy and in providing and distributing funds for effective services to persons and communities affected by HIV/AIDS as we enter the second generation of the epidemic.

We convened this meeting in Brooklyn, a borough in New York City with diverse minority communities and, unfortunately, a borough with a disproportionately high number of AIDS cases. We recognized and were reminded repeatedly by CBO's that day-that AIDS funding is still not reaching populations where the need is greatest, such as minority women and children with HIV/AIDS, gay men of color, substance users, people over 50, incarcerated persons, immigrants and others.

The goal of this meeting was to bring together key service providers, community leaders, and people with HIV/AIDS from New York and New Jersey for a dialogue on current HIV/AIDS programs and policy needs. It linked federal HHS officials who oversee HIV/AIDS related programs, policy and funding guidelines with community based organizations that serve persons with HIV/AIDS and their families in communities everyday. Dr. Marsha Martin, Special Assistant to the Secretary of the Department of Health and Human Services, set the tone by exhorting the CBO's to: "... call us and tell us what we need to know, you need to help us change our language and change our programs if that's what we need to do" All who participated were committed to taking an honest look at what is effective and what is not. The



meeting's format was created so as to ensure that participants had an opportunity to speak and engage in discussions with public officials.

It opened with updates by HHS officials on federal HIV/AIDS programs and initiatives followed by presentations from AIDS service organizations and persons living with HIV/AIDS. We then had a discussion of HHS HIV/AIDS programs and issues continued in depth, followed by questions from the participants. Next, we divided into workgroups where we had presentations on specific topics as well as questions and answers sessions. We concluded each workgroup with a list of recommendations to HHS developed by the participants.

The workgroup topics were as follows: a) HIV/AIDS Care, Children and Families; b) HIV Prevention and Education, Women and HIV/AIDS; c) HIV/AIDS and Substance Use, Minorities and HIV/AIDS; d) HIV/AIDS Clinical Trials, AIDS Treatment; e) Discrimination Concerns, Social Security Benefits; f) HIV/AIDS and Medicaid, HIV/AIDS and People over 50. The HHS agencies represented were: Health Resources and Services Administration, Centers for Disease Control and Prevention, Health Care Financing Administration, National Institutes of Health, Administration on Aging, Administration for Children and Families, Substance Abuse and Mental Health Services Administration, Office for Civil Rights, Federal Drug Administration and the Public Health Service.

We know that Health and Human Services programs and services have played a critical role in addressing the needs of people with HIV/AIDS nationally. Partnerships with state and local government agencies, community advocates, and people living with HIV/AIDS have been essential to ensuring that HIV/AIDS programs are comprehensive, that they are culturally sensitive and scientifically sound. The Congressional Black Caucus Initiative and the money it has provided has started the path toward addressing racial disparities in HIV/AIDS services and programs.

This document is a challenge to us to not just continue as we have, but to stop and listen and most importantly-to dare to make changes, so that we reach those communities with the greatest need and provide resources to the organizations who are on the front-line servicing people with HIV/AIDS. It is our goal to measure the effectiveness of HHS programs and services as the AIDS epidemic has shifted. I hope

are on the front-line servicing people with HIV/AIDS. It is our goal to measure the effectiveness of HHS programs and services as the AIDS epidemic has shifted. I hope that you will take the time to review the recommendations for each workgroup as they encompass current issues from a collective community perspective.

I would especially like to note the extraordinary work and dedication of the Regional Director's Work Group on HIV/AIDS, Sandra Estepa, and Ellen Watson-without whom these efforts would not have happened; Barbara Chocky for her commitment and perseverance; as well as Shirley Turner, Anna Vega, Genet Harnarain and Tamika Bell for their support of this important meeting.

As we confront the second generation of the AIDS epidemic, HHS must continue to provide HIV/AIDS prevention, care and treatment, and research-but do so across the racial ethnic, age, gender and socio-economic lines. HIV/AIDS has been and continues to be a high priority for the Department of Health and Human Services. It is our hope that this report on the partnership efforts in our Region assists in the ongoing development of HIV/AIDS-related HHS programs and policies. To all those who participated in this important meeting, I thank you for your work and for your continued commitment to persons with HIV/AIDS in this Region. Our work continues.

Alison E. Greene  
Regional Director  
Northeast and Caribbean Region  
U.S. Department of Health & Human Services





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# **INTRODUCTION**

# **PLENARY PANEL**



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**Northeast and Caribbean Region  
HHS Community Meeting on HIV and AIDS:  
Confronting the Second Generation of the Epidemic**

## **Introduction**

Alison E. Greene, J.D.  
U.S. Department of Health and Human Services, Northeast and  
Caribbean Region

Eugene Feigelson, M.D.  
SUNY Downstate Medical Center

*"I want to stress that this is a unique  
opportunity for communication between HHS  
officials and the community. This is not the end  
of the process, this is not a one-shot deal, this is part  
of a continuing partnership."*

–Alison E. Greene  
Regional Director

Region II's Community Meeting on HIV/AIDS, "Confronting the Second Generation of the Epidemic," was held on January 14, 1999, in Central Brooklyn, a part of New York City that has a high incidence of HIV and AIDS. It took place on the campus of the State University of New York Downstate Medical Center, an academic medical center that serves Brooklyn's HIV and AIDS population through its HIV Center for Women and Children and HRSA-funded AETC unit.

The meeting was opened by the interim president of SUNY Downstate, Dr. Eugene Feigelson, who noted that the campus was pleased to open its doors to the community and HHS to facilitate this important dialogue. He also noted that

[T]he changing face of AIDS requires a new approach to a disease that was first diagnosed 17 years ago. Here at SUNY Downstate, many of the programs we've developed to protect those at risk have become models for health-care institutions throughout the country. We are at the forefront nationally in studying the epidemiology of the disease among women and children.

Our work has demonstrated again and again that there is hope that those with HIV disease can enjoy healthy lives and continue to contribute to our community. That the spread of AIDS can be prevented with education programs that are sensitive to the people they are intended to serve. Above all, as an academic medical center, we have learned that we are most effective when we work in partnership with the community. That is why today's meeting is so important.

Dr. Feigelson introduced Alison Greene, Regional Director of HHS' Northeast and Caribbean Region . Ms. Greene was appointed to this post by President Clinton and HHS Secretary Donna Shalala. In 1994 she received the Secretary's Award for Distinguished Service for her efforts in forming partnerships to improve public health and she currently serves on the United States Committee of the 1999 United Nations Year of the Older Person.

Ms. Greene noted that due to inclement weather, several scheduled panelists from Rockville, Maryland, and Washington, D.C., were unable to attend. On behalf of Secretary Shalala and the Department of Health and Human Services, she commended audience participants for braving a severe ice storm to ensure the success of what she termed an "historic community meeting."

The agencies that make up the Department of Health and Human Services, Ms. Greene said,

[h]ave played a critical role over the past 18-19 years in the fight against HIV/AIDS. We have accomplished a lot in partnerships with local governments, with the states, with community-based AIDS service

organizations, and with people living with HIV/AIDS to eradicate this disease. We need to proceed together to carefully take stock of what has worked well in the past and is working well now, what is not working well, and where we have to make changes for the future. That is why we are here. We not only want to hear from you, we *need* to hear from you. That is why we're in Brooklyn.

Ms. Greene explained that the goal of the Community Meeting was to provide an overview of HHS's current and upcoming HIV/AIDS programs and initiatives, and to give participants an opportunity to provide HHS with feedback and recommendations through several formats: 1) a Public Comment forum; 2) workgroup recommendations, and 3) a participant's survey. She said,

[O]ur Administration has made an unprecedented commitment to battle this epidemic on many fronts. And we have made a difference. The National Center for Health Statistics announced last October that the age-adjusted death rate from HIV infection in the United States declined by an unprecedented 47 percent from 1996 to 1997.

HIV fell from 8<sup>th</sup> to 14<sup>th</sup> place among leading causes of death for the same period. But, Ms. Greene noted, there is also alarming news. Recent data shows that while over-all AIDS deaths are down, AIDS remains a severe and ongoing crisis in African-American, Hispanic, and Asian Pacific Islander populations, and other racial and ethnic minority communities as well. It is the leading killer of African American men aged 25 to 44, and the second leading killer of African American women in the same age group. The largest percentage of increases in HIV/AIDS cases is now among women and youth, racial and ethnic minorities, and injecting drug-users and their sexual partners. "Part of the Clinton Administration's response to the disproportionate burden of AIDS in racial and ethnic minorities," Ms. Greene said, "is outreach to those communities most heavily affected."

Ms. Greene also described how HHS had joined with President Clinton and the Congressional Black Caucus to announce a special package of initiatives aimed at



reducing the disproportionate burden of HIV/AIDS on racial and ethnic minorities. Fiscal year 1999 appropriations included an additional \$156 million to enhance the federal response to HIV/AIDS in racial and ethnic minority communities. The funding will be used to make crisis-response teams available to highly impacted areas, enhance HIV/AIDS prevention efforts in these communities, and reduce disparities in treatment and health outcomes for minorities with HIV/AIDS.

Ms. Greene concluded,

[I] ask that you direct your energies today to communicating to us your concerns, issues, and recommendations for improving the delivery of HIV services as well as successes and models that do work. Your comments and recommendations will be compiled into a report forwarded to Secretary Shalala, and all relevant people at HHS. I want to stress that this is a unique opportunity for communication between HHS officials and the community. This is not the end of the process, this is not a one-shot deal, this is part of a continuing partnership.

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**Northeast and Caribbean Region**  
**HHS Community Meeting on HIV and AIDS:**  
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## **Plenary Panel**

**Sam Dooley, M.D.**  
**Centers for Disease Control and Prevention**

*“Partnerships are critical because the epidemic is large, complex and evolving. Controlling and eliminating the epidemic will involve partnerships among many different types of organizations.”*

An overview of the Centers for Disease Control and Prevention's (CDC) HIV/AIDS programs, and the funding available for these programs, was provided by Sam Dooley, M.D. As chief of the Community Assistance Planning and National Partnerships branch in the Division of HIV/AIDS Prevention at the CDC, Dr. Dooley is part of the division's senior management team and assists in the development of policies, strategies, and programmatic priorities related to HIV/AIDS and prevention in the United States. He also provides management and oversight for several national HIV prevention programs and activities, including cooperative agreements with 65 cities, states, and territories, 22 national and regional minority organizations (NRMOS), and 94 community-based organizations (CBOs) serving high-risk populations.

Dr. Dooley gave a brief overview of HIV-prevention programs at the CDC. Increasingly, he said, this epidemic is affecting communities of color and doing so in a disproportionate way. He noted that the CDC's HIV mission is to prevent HIV infection and to reduce the incidence of HIV-related illness and death in cooperation with community, state, national, and international partners:

[T]he two key words are: prevent and partners. While we do have programs for secondary prevention—that is, preventing those already infected to progressing to AIDS and developing opportunistic infections—our major focus is on primary prevention. This means preventing people from becoming infected with HIV.

Partnerships, said Dr. Dooley, are critical because the epidemic is large, complex, and evolving. Controlling and eliminating the epidemic will involve partnerships among many different types of organizations.

Dr. Dooley gave a basic overview of CDC programs. These include:

- **Disease monitoring.** Surveillance for AIDS and HIV. These programs define the epidemic for the CDC and provide information on who is becoming infected, where that is happening, when it is happening, and what the trends are.
- **Laboratory, behavioral, and epidemiologic studies.** This category includes two types of studies. The first allow the CDC to learn more about how and why the epidemic is spreading, while the second identify interventions that can be used to help control and eliminate the epidemic.
- **Programmatic activities.** These provide support for local and state prevention activities, both governmental and nongovernmental. They include a public information network and educational programs in schools.
- **Evaluation activities.** These studies examine what works and what does not, and allow the CDC to evaluate how to make its efforts more effective.

Dr. Dooley also focused on CDC support for state and local prevention activities. Funding is provided to 65 state and local health departments (the 50 states, the District of Columbia, six cities—including New York—that are funded separately from their respective states, Puerto Rico, the Virgin Islands, and six Pacific Territories) to conduct HIV-prevention community planning and to provide HIV-prevention services. The CDC allots about 5 percent of its HIV/AIDS budget to



community planning programs. The rest funds a wide array of HIV prevention services, from counseling and testing, to health education and risk-reduction activities at the individual, group, and community level. The CDC also funds public information campaigns to increase public awareness of the epidemic, dispel myths, and decrease discrimination directed towards individuals with HIV and AIDS.

A substantial amount of money is available to prevention providers in the community. Of the money disbursed from the CDC to state health departments, over 50 percent goes to local providers, and 40 percent to community-based organizations.

Dr. Dooley described HIV-prevention community planning as a relatively unique process in public health that

[ i ]nvolves a shared responsibility for setting priorities for HIV prevention within local communities—that is, shared between the health department and the community. This is done through the formation of a community planning group, which includes and is primarily made up of representatives of the community. It is intended to focus on addressing local trends in the HIV epidemic in a way that we are not able to do from the national perspective. This allows you to look at the epidemic as it exists in your own community, which can be very different than even in the town next door. And finally, this planning process is intended to ensure that HIV prevention programs are comprehensive and culturally and scientifically sound.

Dr. Dooley said that prevention planning is a relatively recent innovation. Prior to the initiation of this program some six years ago, there was little opportunity for community members to have input into prevention planning activities. Dr. Dooley noted that while the process is not perfect, it is a significant improvement over what had existed previously, and it allows the CDC to address prevention needs at the local level. "Improving community planning so that it serves the community more effectively is probably our major priority," he said. "There is a

tremendous need for involvement of people in the community.”

In addition to funding health departments, the CDC also provides direct funding to CBOs. Ninety-three such organizations are currently funded. The CDC’s Program Announcement 704, Dr. Dooley explained, predominantly focuses on CBOs targeting high-risk populations that are managed and staffed by people from racial and ethnic minorities providing services to their communities, including, for example, street outreach and/or prevention case management. The CDC, Dr. Dooley said, believes “these organizations are particularly effective in providing interventions that are culturally appropriate and specific to the local community.”

The CDC recently received a new appropriation of approximately \$18 million to address the needs of disproportionately affected racial and ethnic minority communities. About \$10 million of the \$18 million will be used to fund approximately 40 additional community-based organizations. According to Dr. Dooley, getting this money out to programs in the community is a major CDC priority. “In our branch, we currently have all of our efforts focused on this process,” he said. “It is an involved process with many steps.”

These include developing the program announcement, obtaining appropriate clearances, obtaining consultation from external groups, getting public comment through publication in the Federal Register, making certain that there is technical assistance available to CBOs that are interested in applying to help them with the grant-writing process, and then actually reviewing the applications and making the awards.

Normally, from start to finish, approval takes between a year to a year-and-a-half. Dr. Dooley said the CDC hopes to compress this time to seven months. Program announcements are expected to be out this spring, with awards made before the end of September. He cautioned that while the CDC can’t absolutely promise to hold to these dates, “they are the targets that we are aiming for, and we are hopeful that we can achieve them.”

In addition to funding organizations that provide HIV-prevention services,



the CDC also funds organizations that provide technical assistance (TA). It works with a variety of organizations, including contractors, consulting groups, and academic institutions. One major program, for example, funds 21 national and regional minority organizations that provide consultation, technical assistance, and training services to help community-based organizations build their capacity to provide HIV prevention services.

The types of technical assistance provided typically include development and governance, cultural competency, program development and evaluation, resource development, fiscal management, human resources management, and so forth. “So it is primarily operational/organizational type of technical assistance,” Dr. Dooley said, “although they also provide TA in other areas.” Four grantees are providing technical assistance for community planning and six have been working on an assessment of the technical assistance needs of CBOs. Their report, which has just been completed, is helping the CDC redefine its technical assistance network.

Dr. Dooley also discussed recently approved increases in appropriations for the CDC. Of the \$18 million new dollars that were appropriated for the CDC, some \$2.2 million will be used to fund additional NRMOs (national and regional minority organizations) to provide technical assistance, with a program announcement timeline similar to that of the CBOs. “It is running a little bit behind,” he noted, “because we want to put the primary focus on getting the money out to CBOs, but it will be not very far behind that.”

The CDC also funds other types of partnerships involving business, labor, and faith organizations. About \$1.5 million will be used to help faith-based organizations provide HIV prevention services to their communities. Another \$4 million will be used to fund community development demonstration projects aimed at developing and creating links among HIV-prevention and sexually transmitted disease (STD), tuberculosis (TB), substance-abuse treatment, and other care programs that are heavily affected by HIV.

In conclusion, Dr. Dooley mentioned the CDC's national public information network. Previously called the National AIDS Clearinghouse, it has been renamed the National Prevention Information Network. This can be a valuable resource to identify AIDS programs and services around the nation.

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**Northeast and Caribbean Region**  
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## **Plenary Panel**

**Douglas H. Morgan, MPA**  
**Health Resources and Services Administration**

*It is incumbent upon we at  
HRSA who fund the bulk of care  
in this country to make sure that services are  
accessible to everyone who needs them.  
That's our general goal."*

The second panelist was Douglas Morgan, director of the Division of Service Systems of the HIV/AIDS Bureau within the Health Resources and Services Administration (HRSA) of the Department of Health and Human Services. Mr. Morgan outlined the responsibilities of his division, which administers bureau programs and manages funds and other resources related to the provision of coordinated, comprehensive HIV health care and support services.

Mr. Morgan reviewed HRSA's mission, how HIV/AIDS programs funded by the Ryan White CARE Act are organized within HRSA, and the agency's efforts to confront the epidemic. He also discussed the Congressional Black Caucus Initiative.

HRSA is one of several agencies under the U.S. Department of Health and Human Services. One of its primary goals is to increase access to basic health care for

those who are medically underserved. Its program portfolio includes over 80 distinct initiatives designed to increase access to care, improve quality, and safeguard the health and well-being of the nation's most vulnerable populations.

In regard to its mission of increasing access, Mr. Morgan explained that HRSA is guided by four principles. Health-care services must be: 1) comprehensive and coordinated; 2) of the highest quality; 3) community-based; and 4) culturally competent.

A key objective of HRSA is to achieve a 50 percent decrease in HIV-related mortality by the year 2003. By the year 2002, said Mr. Morgan, "we want to see at least 90 percent of those who are diagnosed as HIV-positive in care within six weeks of diagnosis. That is a substantial activity that will require help from many sources."

Within HRSA, all of the CARE Act programs are overseen by the HIV/AIDS Bureau. In Fiscal Year 1999, the CARE Act received almost \$1.5 billion in new appropriations. Title I of the CARE Act provides grants to 51 eligible metropolitan areas, including the City of New York, while Title II provides grants to the 50 states, the District of Columbia, and a number of territories, including Puerto Rico, the Virgin Islands, and Guam. Title II also funds the AIDS Drug Assistance Program (ADAP). In Fiscal Year 1999, ADAP was funded at \$461 million dollars, a substantial increase over its initial funding of \$52 million in 1996.

Title III of the CARE Act targets community-based programs and provides dollars for early intervention services around the country. It is administered by Deborah Parham, who heads up the Division of Community Based Services. This division is also responsible for Title IV, which provides services to pediatric and clinical research centers around the country. There is no Title V of the CARE Act per se, but there is a part F, the AIDS Education and Training Center (AETC) Initiative, which funds some 16 AIDS Education and Training Centers around the country.

Mr. Morgan noted that the HIV/AIDS Bureau has identified four trends that will shape policy over the next decade:



- First, that the HIV/AIDS epidemic is growing among traditionally underserved and hard-to-reach populations.
- Second, the quality of emerging HIV/AIDS therapies can make a difference to the lives of people living with HIV disease.
- Third, changes in the economics of health care are affecting HIV/AIDS CARE networks.
- Fourth, policy and funding are increasingly determined by outcomes.

To reach the first goal—recognizing that underserved and hard-to-reach populations are the target of this epidemic—HRSA has increased funding for early intervention services and planning grants for rural and underserved areas. It has also funded a number of innovative models of care for historically underserved and hard-to-reach populations. Telehealth, for example, uses new technologies to help educate people in isolated and rural communities. HRSA and the Office of Advancement of Telehealth will soon sponsor a demonstration program that uses video conferencing and the Internet to educate physicians in rural parts of the country.

To help achieve its second goal—recognizing the benefits of therapies—HRSA has substantially increased appropriations for ADAP (AIDS Drug Assistance Program). New York's ADAP program, for example, has seen increased growth as a result of this funding. Because of ADAP and other initiatives that increase accessibility to AIDS therapies, a number of sites have reported dramatic declines in perinatal HIV transmission.

The third guiding principle addresses economic changes affecting HIV/AIDS care. Mr. Morgan said, "I need not tell this audience that managed care is sweeping the country." Medicaid is a principle "player of payer" for HIV/AIDS services but it is also moving to managed care at a very rapid pace. Because of this, HRSA has been working with a number of grantees to improve their ability to survive within a managed care environment. For example, six demonstration programs funded by SPNS (Special Projects of National Significance) grants are working to develop



innovative methods to survive under managed care. The HIV Bureau has been working collaboratively with HCFA (Health Care Financing Administration) to ensure that HIV/AIDS care does not get lost in the managed care environment and that quality care is provided by managed care plans.

The fourth principle, that of evaluating outcomes data, has meant that HRSA has been working with grantees to gather and analyze program information on both the numbers and demographic characteristics of persons served, in order to report on the impact of CARE Act dollars to Congress. The agency is working jointly with the Centers for Disease Control to make it easier for grantees to report data and information.

Mr. Morgan also discussed the Congressional Black Caucus Initiative, and the effect it has had on HRSA programs. Under that initiative, HRSA received \$12 million in new dollars in fiscal year (FY) 1999, broken out as follows: \$5 million to supplement Title I grants; \$3 million to fund some 60 new planning grants under Title III; \$2 million for Title IV; and an additional \$2 million to AETCs to increase clinical training provided by Black colleges and universities. Mr. Morgan said,

[T]he \$5 million that was appropriated to Title I of the CARE Act was specifically directed to efforts that seek to improve the quality of care and health outcomes for African Americans living with HIV/AIDS in EMAs (Emergency Medical Areas). Because there are 48 EMAs, \$5 million is not a lot of money. To put this amount in perspective: The entire Title I appropriation this year was in excess of a half a billion dollars, so \$5 million represents one percent. It's a small amount of money in the context of the larger picture, but we are hoping it will make a significant difference. We are working with the EMAs to do that.

Under Title III, approximately \$3 million will be available to fund some 60 new planning grants. An RFP (Request for Proposals) will be sent out in spring of this year, asking for responses from eligible agencies. "It is our hope," said Mr. Morgan, "to fund all 60 of those planning grants. We are hopeful that additional

dollars will be made available for operational costs. At this time, however, I can't tell you the exact amount that will be available."

Under Title IV, HRSA wants to address the prevalence of HIV/AIDS among African-American children. African American and Latino children comprise about 80 percent of the 8,000-odd cases of pediatric AIDS in this country. "Clearly, we want to reduce perinatal transmission and to reduce the incidence of HIV/AIDS in communities of color," said Mr. Morgan. "We are working with our current grantees and hope to provide additional dollars for this." Mr. Morgan concluded,

[W]e at HRSA recognize the importance of working collaboratively with other agencies battling the HIV/AIDS epidemic. We are in the second decade of this epidemic. It is clear to all of us that we can now make a difference in the quality of life of people living with HIV infection. But you can't do that unless people, first, know their serostatus and, second, if they are positive, get into care. It is incumbent upon all of us to work collaboratively with prevention efforts that identify people who are at risk and provide counseling and testing services to ensure that people who are positive get into care. We at HRSA who fund the bulk of the care in this country must make sure that these services are accessible to everyone who needs them. That is our general goal and that is the philosophy that will be guiding us in years to come with respect to this epidemic.



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## Northeast and Caribbean Region

### HHS Community Meeting on HIV and AIDS:

Confronting the Second Generation of the Epidemic

## Plenary Panel

Eric Goosby, M.D.  
National HIV/AIDS Policy Office

*Resources, especially the new dollars  
that have been made available, need to be applied  
to strategies that are effective in identifying and retaining  
individuals in care and services.*

Dr. Eric Goosby is the director of the National HIV/AIDS Policy Office at the Department of Health and Human Services Office of Public Health and Science, formerly—and still—known as the Public Health Service. In this capacity, Dr. Goosby serves as the principal AIDS advisor to the Assistant Secretary for Health and Human Services, the Surgeon General, and the Deputy Secretary for Health and Human Services. He oversees HIV/AIDS budgetary development for all Public Health Service Agencies and advises on all AIDS policies, programs, and activities for HHS.

Dr. Goosby discussed the impact that HIV and AIDS have had on communities and individuals, and spoke eloquently on harm reduction. He argued that with appropriate intervention strategies, the progression of HIV and AIDS



through populations can be strategically blocked.

[W]e have watched this epidemic evolve over the past 17 years, and have seen an extraordinary amount of suffering and mortality associated with it. Given the number of individuals who have been infected and who have succumbed to the disease and the potentials that have been unrealized, we will never really recover—as a country, as states, as cities, as individuals. Every one of us, in our work and in our personal lives, has been affected and impacted by the personal tragedies that this virus projects on the individuals that it infects and on those that love them.

Dr. Goosby noted that health policy makers can no longer tolerate indifference or a lack of engagement toward individuals who potentially could be infected, especially since the science of treating HIV has reached a point where the progression of the virus can be slowed or, in some cases, close to arrested. “We no longer can say that we don’t know what to do. We do know what to do,” he argued.

There are now prevention intervention models that effectively curtail behavior patterns that increase the potential for transmission. The Department of Health and Human Services and the Clinton Administration, Dr. Goosby said, are committed to ensuring that these practices be rapidly articulated, defined, and implemented. “This administration has attempted to put the resources behind the science, and has pushed this effort over the last six to seven years to the highest priority within the Department of Health and Human Services.”

High-risk populations need to be targeted, Dr. Goosby said. “We must actively engage these populations in a dialogue around the potential for transmission and work with them to effect behavior changes that minimize the risk of transmission and better ensure their ability to sustain themselves in their environment.” Those who are seropositive need to be identified and embraced within a system of care that is respectful and gender and culturally sensitive. It must also repetitively, over time, offer multiple opportunities to be engaged in a continuum of



care and services.

Dr. Goosby said that government agencies at all levels—federal, state, and local—have an obligation to ensure that individuals with HIV and AIDS are offered the highest level of quality care. “The complexity of antiretroviral therapy, the ability to maintain an individual at the lowest possible viral load, the need to anticipate changes in opportunistic infections and malignancies, as well as psychosocial needs, all these must be orchestrated around each individual, so that each person can be retained in care and services.”

Services need to be geared toward encouraging people with HIV and AIDS to re-engage in a normal life and to re-enter an active interchange with society. Dr. Goosby also cautioned that those who make health-care policy need to acknowledge that there are individuals within the population who are less likely or unable to reveal themselves to society and their immediate community, for fear of retribution or condemnation.

The changing demographics of the epidemic also need to be acknowledged, and individuals who are at the forefront of the seroconverting population— injection drug users, women, and minorities—need to be integrated into systems of care. Resources should be applied to strategies that effectively identify and retain individuals in care and services. This means creating tight linkages between prevention and treatment programs. It means making substance abuse, which has always been peripheral to core medical service delivery systems, central to treatment. It means educating the provider staffs that interface with these populations on the importance of the overlay of substance abuse and mental illness, and how it affects ultimate outcome.

[N]o longer can lack of capacity in a community be viewed as the sole reason for individuals not accessing a delivery system. We need to look at our populations at high risk. We need to go backward from the population into the delivery system and examine every point of access that is potentially there—from family planning clinics, to TB clinics, to STD (sexually-

transmitted disease) clinics, to community health centers, and to emergency rooms, as well as to our HIV-dedicated centers. Prevention intervention systems need to be one point in a net that can be thrown over a population. Access should be such that a person can access any service-need from any one point. It is vitally important for us to realize that this is doable, and that we can do it with relatively small amounts of resources.

Another issue that needs to be acknowledged by healthcare policymakers is the role that injection drug use plays in driving the epidemic, and that society's systems of care have disenfranchised the drug injecting population out of the delivery system. Rather than treatment, legal and law enforcement systems are their main interface.

Dr. Goosby articulated a different vision, one that he said is possible and achievable. In his own practice, he said, he has had success in reaching difficult populations.

[W]e are talking about a disease process that is treatable, and one that has a high probability of success given effective and repetitive opportunities to interface with a knowledgeable delivery system. These include: the ability to use needle exchange programs as outreach mechanisms, to engage individuals who are 'actively using' in a dialogue when they come into exchange, and having multiple and repetitive opportunities to engage that individual in prevention messages and in a dialogue around the utility of therapeutic interventions.

Dr. Goosby noted that in his own practice, he has successfully treated many patients with antiretrovirals who are homeless or actively engaged in injection drug use. "If you meet them in a nonjudgmental but honest fashion, you can retain them in care and services." The homeless population also needs special accommodation. It is essential to link homeless shelters with medical, substance abuse, and mental health

services. Once this occurs, said Dr. Goosby, “the stability that comes into these individuals lives is extraordinary, especially if it can be matched with social services that pull people into a stable living arrangement and not one where they are displaced every 12 hours.”

Dr. Goosby also discussed problems in HIV and AIDS care in minority communities. He said it has been evident to the Department of Health and Human Services and the Clinton Administration that minority communities are disproportionately impacted by HIV and that this problem is compounded because programs that serve minority communities often have infrastructure deficits that block funding of Ryan White-type programs. He added that minority communities are also burdened by a lack of ownership of HIV as a disease that impacts their population, and this in turn has resulted in sustained, negative consequences for those who reveal themselves to the community—for themselves, as well as for their families.

[T]he hesitation that black men of color have expressed in focus-group discussions with the Department [of Health and Human Services] around what the church membership will think of them, and most importantly, how it [the congregation] will react to a mother or father who continues to participate in the congregation, is an extraordinary, negative impetus to engagement in a delivery system. We need to address this issue. We need to work on it as aggressively as we do the quality of providers and their knowledge of antiretroviral therapies. We need to engage leadership within these populations to define strategies that will be effective in embracing this population.

Dr. Goosby concluded with a review of the Congressional Black Caucus initiative which, in conjunction with the Department of Health and Human Services and the Clinton Administration, is working to direct resources to areas of need.

"It is not the first effort we have made," said Dr. Goosby, "The first efforts began in 1993. The Department can be proud of the record its programs have had in reaching underserved populations. But we have not been successful in embracing this population and the data has clearly shown this. We are committed to the success of this effort."



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**Northeast and Caribbean Region**  
**HHS Community Meeting on HIV and AIDS:**  
Confronting the Second Generation of the Epidemic

## **Plenary Panel**

**Marsha Martin, D.S.W.**  
Department of Health and Human Services

*"We are here now to say that we want to facilitate and improve our partnerships so that we can respond to this epidemic in a different way."*

The final panelist of the Plenary Session was Marsha Martin, D.S.W., Special Assistant to the Secretary of Health and Human Services, Donna Shalala. Dr. Martin advises the Secretary on issues related to AIDS, homelessness, and the special concerns of vulnerable populations. She also serves as a liaison to the Department's broad constituencies, including ethnic and racial communities, gay and lesbian communities, and homeless families and youth, with a focus on health concerns.

Dr. Martin told conference participants that she would "talk about why we're here; why we're here in terms of the 'feds'; what we need to learn, know, and do; where we go from here; and a little bit about what a few people can do."

Why did the Department of Health and Human Services decide that a series of regional and national conferences across the country were necessary? In Washington, Dr. Martin said, everyone is talking about the changing face of AIDS and how the demographics have shifted. "However, we haven't gone out and had a conversation with that face. We haven't heard from the voices of the people that we talk about 'inside the beltway.'" According to Dr. Martin, the Secretary of HHS recognized that given current statistics, the Department could not adhere to the same paradigm and agenda. She also recognized that HHS could not change its focus of "So

we're here because you need to tell us what you need to know about we're doing," said operations without having a dialogue with those who live in affected communities. Dr. Martin. "We need to know how we can enhance our programs and how we can change them. If what we're doing doesn't seem to apply or fit with what you're seeing, experiencing, and responding to, we need to know that." She added,

[W]e need you to take our request seriously. I want you to participate in the discussion and dialogue. We need your comments if we're going to change eligibility for Medicaid or reconsider what drugs are going to be made and how much money will be spent on our drug assistance program. We want you to tell us about how treatment guidelines are being applied in your clinical care settings, and whether everybody who is eligible for Medicaid is receiving Medicaid. When they go to use their Medicaid card, are they receiving the clinical services that the federal government has established as the standard? You need to tell us. And that's why we're here.

Dr. Martin said the Department hoped to gather the facts and figures it needs to influence the federal response to the HIV and AIDS epidemic. "I want everyone in this room to know that they can participate and that we can learn from you about what we have to do differently. We're public officials, our telephone numbers are public information. You need to call us and tell us what we need to know."

Dr. Martin told conference participants that the afternoon workshops had been organized along a matrix that reflected the HHS divisions charged with responding to the epidemic. These include prevention, clinical intervention, care and services, research, policy agenda, and population agenda. She asked everyone to join in the workshops, and through their participation, help HHS understand the nuances of what works and what doesn't. In the United States, Dr. Martin explained, funding for the AIDS infrastructure amounts to some \$7.7 billion, including monies appropriated between the Veterans Administration, HUD (Housing and Urban Development), HHS (Health and Human Services), and the State Department. That

figure doesn't encompass resources allocated to international organizations through the International Monetary Fund and the World Bank.

That figure, \$7.7 billion, is substantial. However, said Dr. Martin, funding has not followed the epidemic's demographic patterns. She described how a few individuals helped to change this picture, when 33 leading AIDS activists came to Atlanta to advocate for change. These activists told the CDC that new and innovative approaches to the epidemic were needed and that the epidemic was so severe that the federal government needed to listen to those who were on the frontline. She added,

[T]hat's what a few people can do. They decided that they couldn't leave Atlanta without a commitment from this Administration that HIV/AIDS in the African American and ethnic racial minority communities be declared a crisis and a national public health emergency. They took that energy to the Congressional Black Caucus, which then joined with them in a dialogue with the Secretary and Surgeon General and, ultimately, the President of the United States that resulted in \$156 million in new dollars directed at HIV/AIDS in the African American, Hispanic, Asian/Pacific, and Native American communities.

What a few people can do is really important. And what you can do is really important. I'm here representing the Secretary of Health and Human Services. Everyone here is representing divisions and programs, resources and funding streams, and policies and regulations. *We* are it at HHS, and we are here to facilitate a new partnership around HIV and AIDS. Facilitate means to make easier. Partnership is about people being on the same side, trying to do something together. So we are here now to say that we want to facilitate and improve our partnerships so that we can respond to this epidemic in a different way.

Dr. Martin then passed out 3 x 5 cards and asked conference participants to note on them, both as individuals and organizations, how a small grant from HHS (say, \$25,000 to \$50,000 dollars a year for three years) could best be used. "We're

going after capacity development money, support to strengthen your capacity to do what you're doing. You tell us, what could you use that money for?" Dr. Martin said the information she received on these cards would be relayed to the Office of Management and Budget.

This concluded the Plenary Panel session. A short break was taken before proceeding to the Public Comment period.



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# **PUBLIC COMMENT**



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## **Northeast and Caribbean Region**

### **HHS Community Meeting on HIV and AIDS: Confronting the Second Generation of the Epidemic**

## **Public Comment Period**

The Public Comment period allowed participants to air their issues and concerns, both to the panelists and to HHS. This section of the Community Meeting was moderated by Sandra Estepa, Regional Women's Health Consultant for the U.S. Public Health Service, Region II. Ms. Estepa reviewed the guidelines and asked that comments be limited to two minutes. She also asked organizations to limit their representation to one speaker only, in order to allow for maximum participation and the broadest spectrum of community opinion during the Public Comment Period. Those who had indicated on their pre-registration form that they wished to speak were called first, in the order that they registered; when the list of registered speakers was exhausted, the floor was opened to anyone who wished to speak.

The rules were delayed to allow Beny J. Primm, M.D., Executive Director of the Addiction Research and Treatment Corporation, Vice Chair of the National Black Leadership Commission on AIDS, and incoming Chair of the National Minority AIDS Council, to address the audience through a special brief presentation. Dr. Primm provided an overview of the struggle of community providers and advocates to ensure that the Department of Health and Human Services provides the resources necessary to respond to the ongoing crisis and continuing toll of HIV/AIDS in African American and minority communities. Dr. Primm also highlighted recent efforts by Black leadership groups and the Congressional Black Caucus to obtain additional AIDS funding for minority communities across the nation hard hit by HIV/AIDS.

Following Dr. Primm, 28 individuals presented Public Comment to the Plenary panelists, who included Sam Dooley, M.D., Chief of Community Assistance Planning and National Partnerships, Centers for Disease Control and Prevention; Eric Goosby, M.D., Director of the National HIV/AIDS Policy Office, Department of Health and Human Services; Alison Greene, Regional Director, U.S. Department of Health and Human Resources, Region II; Marsha Martin, D.S.W., Special Assistant to the Secretary, Department of Health and Human Services; and Douglas H. Morgan, M.P.A., Director of the Division of Service Systems, HIV/AIDS Bureau, Health Resources and Services Administration. Because of the importance of the Public Comment Period, remarks have been transcribed verbatim, with minor editing.

**Beny J. Primm, M.D.**

**Addiction Research and Treatment Corporation**

Let me begin by thanking Alison Greene [Regional Director, U.S. Department of Health and Human Services, Region II] and Sandra Estepa for allowing me the opportunity to speak for a few minutes concerning issues that I think are very important. And certainly to thank Dr. Marsha Martin from the Office of the Secretary, Dr. Eric Goosby from HHS, and Dr. Sam Dooley from CDC, for all that they have done to allow us to be successful in bringing about the delivery of some \$156 million new dollars to try and stem some of the onrushing tide of problems in the African American community and other communities of color. Now with that preface, I'm going to tell you a few things that I think are so very important to us as a group, and if we begin to work as a group, we can do a whole lot more for the problem that we are trying to do something about.

We are in historic Brooklyn. I have seven clinics here. I am the emeritus chairperson of the Brooklyn AIDS Task Force, which started and was housed in my center. I'm also the chairperson elect of the National Minority AIDS Council (NMAC). In this audience sits someone who goes back to 1983/1984 when we met with our own monies to start NMAC, and that's Suki Ports. I mentioned those



names because I would like you to know that there is a historical background of people, other than those who may be in some of the more known organizations, that have been working for a number of years with this problem.

The first thing I would like to mention is that we're here in Brooklyn and here is the home of Spike Lee's office. He did a movie a few years ago. That movie was "Do the Right Thing." Do the right thing. When I talk about "do the right thing," I'm talking about epidemiologically, when we know the data. We didn't know the data exactly as it was, nor had we heard it expressed like it was, until 33 of us were invited to the CDC and the data was given to us epidemiologically in a fashion that was simple and easy to understand. Seven people every hour, I was told, come down with HIV and AIDS. Three of those seven are African Americans. What more could I do then but become very upset, and begin to try to do something about the problem. So first of all, with epidemiology, we have to do the right thing. Once we know the epidemiology and the data, the money ought to follow the epidemic. And it ought to follow the epidemic just as quick as the epidemic changes. The money should follow so that we can take care of those people who are more severely affected by the problem. Our effort, by the way, was bipartisan, it was biracial, it was bicoastal, because people were from all over the country, and it also was bisexual. So it was all of those things that went into this particular endeavor to make it become real.

Dr. Martin said something in her opening statement. She talked about a new partnership. Let me tell you about new partnerships. Who would ever think that those 33 people who, in a revolutionary fashion, took over a meeting at CDC, would then partner with CDC and then partner with Health and Human Services to bring this about, and then partner with the Congressional Black Caucus? I was quite shocked when I spoke initially to people at the Caucus. I spoke to the Health Brain Trust to help the Congressional Black Caucus, and I spoke to members of the Appropriations Committee. I did that in the reverse order—I spoke to members of the Appropriations Committee first, and it just so happened that one of the

members of the Appropriations Committee was in charge of the Congressional Black Caucus' Health Brain Trust. He then asked a few questions at the Appropriations Committee's hearing for the Centers for Disease Control. Dr. Broome answered those questions. I also spoke to my Congressperson. I want you to hear this. This is very important for your future action. My Congressperson is Nita Lowey. Nita happens to be, also, a member of the Appropriations Committee for Health and Human Services. Wonderful! So once I talked to them and told them about the problem, they were able to answer some very specific questions at the appropriations hearing of the people involved.

You have to make some sacrifices along the way. I funded my own trip to Washington when I was invited to address the Congressional Black Caucus. They heard my hue and cry, and lo and behold, got behind us and did what they had to do. I must mention that you need someone who is a pitbull and who is a spokesperson like [Congresswoman] Maxine Waters. I could not believe what Maxine did in the fight. She was able to negotiate with the [HHS] Office of the Secretary. She called a meeting and invited other people to Washington to come and talk to her. She also invited some of the panelists that you see on this stage. She came and spent the whole day in partnership. Partnership. That's what counts.

Let me talk one minute about the federal effort. I have one problem with that. HHS has done some wonderful things, and I was part of one of the agencies in HHS. I was the former director and the first director of the Office for Treatment Improvement, and the Center for Substance Abuse Treatment in the Substance Abuse and Mental Health Services Administration (SAMHSA). One of the things that was so horrific for me when I was there, was that agencies didn't talk to one another. SAMHSA, for example, hardly talked to the Centers for Disease Control. We hardly talked to HRSA (Health Resources and Services Administration). We didn't talk to HCFA (Health Care Financing Administration). I mean, here we are, intramurally, and not talking to one another. That galled me, because we could have done so much more had we done so. As a matter of fact, I'm concerned about how communications go downwards from the [HHS] Secretary's Office to the office here

Primm, and they knew about Debra Frasier Howze, but our office here, that works for us in this city for Region II, had no idea about us. It's important to rectify that situation. It has to happen.

There are many organizations that worked on this problem. And as I said, they were biracial, bipartisan, they were Democrats, and they were Republicans. Because this particular effort was seen as an effort that could solve the problems of some of the people who were suffering disproportionately from the problem here in the United States.

In conclusion, one of our greatest fears here in New York City now has been realized, as far as I'm concerned. And that is, some [Ryan White CARE Act] Title I funds just recently came to New York City—\$1.2 million. And I hear that the Executive Committee of the HIV Planning Council plans to distribute that money in a manner [that goes against the intent of the CARE Act to support programs and services in communities hardest hit by AIDS]. Now I'm concerned about that. I received a copy of a letter yesterday from the Harlem Directors Group, which has asked me to join with them to perhaps pursue a class action suit, to make sure that the HIV Planning Council begins to look at us [African Americans and other minorities] like they should. The money should follow the epidemic. We have the data. We need somebody to serve as a watchdog in this situation.

I am extremely happy at my age to have been chosen, even after denying that I wanted to serve, as the spokesperson for that group that went to Atlanta. But they saw that maybe with my gray hair and my balding head and my now moving on along, that maybe I would not have any fear. It re-energized me to be even more dedicated to not “dying with my music in me.” I intend to sing every song and to sing it in symphony, not in cacophony. In symphony with those people who suffer from this problem. I'm dedicated to that. Thank you all very much for your time.



## **Victoria Rosenwald**

### **Clinical Directors Network**

I'm here also to say thank you to HRSA (Health Resources and Services Administration), because I'm here to talk about a CARE Act program. Some of you have seen this flyer [held up by Ms. Rosenwald] that says, "Do Your Patients Have Access to Clinical Research?" And the import of my speech is that the answer is always, "yes." This program, Study Link, that's housed at the Clinical Directors Network, is a database of all enrolling clinical research programs that take place in New York City or in the metropolitan area. If there is something we don't know about, please tell us, but we try really hard to find out everything. Along with the tenor of Dr. Primm's speech, I would like to say that we also exist to help people to work together and to talk to each other. It's our feeling that New York City is the epicenter of the epidemic, and should be a center of research. And I would like to emphasize that clinical research is not just treatment research, it's epidemiology, it's observation, it's finding out how things work. I think it means that women who are pregnant should be in a research program to help find out how pregnancy and HIV work. That people who are in the midst of primary or acute HIV infection should be in a research program to help learn about viral dynamics, and how treatments work early in infection. Because there is so much community-based care in New York, the scene can be sometimes fragmented. We exist to help pull it together. I hope that people will call this number. We're here to make it easy for people to refer patients. Call us up.

## **Alice Terson**

### **AIDS Service Center of Lower Manhattan**

I'm representing women who are HIV positive, those who don't know their HIV status, and those who are negative. I coordinate women's services at the AIDS Service Center [of Lower Manhattan]. I have to pose this first question to Alison Greene. You talked about the Women's Summit in New Jersey. I have yet--and the agency I work for has yet--to have any reply to the outcomes of those



recommendations. I'm disappointed. I'm frustrated. And angry. I know it's very successful that we came together. I know one of the successes—I was present for it. Second question: when will successful programs be aimed toward status unknown, HIV-status women, and negative women? When will we come together to strategize, develop, and plan services to meet the multitude of needs of these different populations? I've been working in the field since 1989 and I hear "let's talk." I'm tired of talking. I went to this Women's Summit. I heard numbers. I don't remember numbers—but I know big, and I know small. I know a lot, and I know a little. I don't try to remember numbers. But what I do know is that there are a lot of women becoming infected. I am tired of seeing women becoming infected. What are we doing? I understand prevention—and this is the other point I want to make. What does prevention mean? When you give money to organizations, what does prevention mean? Does it mean "prevention, and we want you to take a pill regularly?" There's a term for that, but I'm not going there. See, I work with a population that I have to keep it very simple. So I'm coming here with a lot of simplicity. Does prevention mean that "I have to take my 10 pills every two hours with this, that, or the other, what kind of foods do I have to take?" Is that what prevention is? Does prevention mean that if you're HIV negative, we assist you in remaining HIV negative? Does prevention mean that I give you condoms without an explanation? Does prevention mean that I give you a set of "works" without telling you that there's something better after that...or that there could be? You see, because some people want to shoot dope until they die. And that's fine. But some people don't. I did. But I don't shoot dope any more. I needed someone to talk to me as they gave me the syringe, because I was around collecting syringes...when ACT-UP was on the Lower East Side, I could get a syringe. But I needed someone to talk to, to give me a better way—not someone to just give me a syringe. This is really important. It needs to be said. I'm really frustrated. And I'm not talking about only Alice's frustration. There are many of us sitting here, and people who are not here today because of the weather who are just as frustrated. We need to know what

is prevention. When we give money for prevention, what are we giving this money for? What do we have in mind? What does that agency have in mind? I don't know that these are questions that are placed in an RFP. I don't know, I don't deal with that level. I do frontline work. Thank you very much.

Response from Alison Greene, Regional Director, HHS Northeast and Caribbean Region:

I want to say, quickly, that the final report from the Women and AIDS Summit will be available shortly. A draft is done, and a draft of the summary of recommendations has been sent to the HHS Secretary's Office. There was so much good material that came out of the Summit that we want to do the report right. Let me assure you that you will receive the final report as soon as it is completed.

**Kimberly M. Mutcherson**

**HIV Law Project**

I am a Staff Attorney for Reproduction Rights for the HIV Law Project here in New York. I'm also here to urge for more action and a little less talk. My agency will be celebrating our ten-year anniversary in the Spring. And throughout those ten years we've maintained our commitment to advocacy for women living with HIV and AIDS. Therefore in my two minutes, I wish to comment on two issues that are critical to women living with HIV. Recognizing, of course, that there are many more important issues for women living with HIV. The first is Secretary Shalala's determination on newborn HIV testing as routine practice for babies whose mothers were not tested for HIV prenatally. I'd like to point out that a lot of women who don't test [for HIV during their pregnancy] are never offered the option of having an HIV test. This determination is vitally important, since her [the Secretary's] decision could lead to mandatory HIV testing of newborns throughout the country, an approach taken in New York State in 1997, and an approach that does not reduce perinatal HIV transmission. I hope that the message of mandatory HIV counseling and voluntary HIV testing as the best approach for the reduction of

perinatal transmission will be carried home to the Secretary by the members of this panel. The second issue I want to talk about is the FDA's (Food and Drug Administration) clinical hold rule. It was in 1995 that the National Task Force on AIDS Drug Development recommended that the FDA create a clinical hold rule, which would allow that agency to halt trials involving people living with life-threatening diseases if those trials excluded women because of their reproductive potential. In 1997, the FDA published a proposed clinical hold rule in gender-neutral terms, and asked for public comment. My agency sent comments and we are aware of at least 100 other agencies and individuals who sent in positive comments on that proposed rule. It is now January 1999, and as far as I know, that final rule still has not been published, which suggests to me and which I think suggests to many other people in this room that there is no real commitment to this rule at the federal level. In the months to come, my office will continue to monitor the rule's progress or lack thereof and also to mobilize the over 700 supporters and members of our Coalition for Women's Choice in HIV Testing and Care, to publicize the continued failure to address gender discrimination in HIV research. Thank you.

**Edward Krales**

### **The Momentum AIDS Project**

Good morning. I'm the Coordinator of Nutrition and Outreach for the Momentum AIDS Project. We have 12 programs in 10 sites around New York City in four of the five boroughs. We have been unable so far to get into Staten Island. I think the best use of my time would be just to scream for two minutes! But I know that would get a lot of people upset, including myself, so I won't do that. [But it would] express the frustration I feel between what we know is real and what we can accomplish. There is a great divide between what the science tells us in HIV and what we're able to implement. And specifically, aside from needle exchange, which of course is the most glaring example of not being able to get that moving, when as we learned this morning it's a primary driver. But in terms of nutrition, we know



from countless studies that nutrition is critical for maintaining good immune system health. We know that nutrition is critically important, particularly with these new protease inhibitor regimens. That if you don't eat properly, and eat on the right schedule, then the medication you are taking is virtually worthless. This didn't start with HIV; a lot of other medications have this problem as well. You have to eat properly or things don't work. I mean, after oxygen and water, food takes over. In spite of this, my agency has difficulty in getting sufficient funds to promote this idea, both in the real sense of serving meals and in the educational sense, in that a lot of things have to be done. But also in terms of the side effects that occur within HIV regimens, such as diabetes. We know that things can be done about that, but we have to train additional people and train our own staff to become certified diabetes educators to get these things done. We've been able to follow the epidemic: 70 percent of our clientele are people of color, 90 percent are poor, 20 percent are women, 10-15 percent are over 50. But if we don't get the funds to move into the right neighborhoods, we are not going to be able to continue our work. Thank you

**Angela Rita**

**Institute for Puerto Rican and Hispanic Elderly**

I'm representing the Executive Director, Suleika Cabrera Drinane, from the Institute for Puerto Rican and Hispanic Elderly. I'm also here on behalf of, and representing, the elderly population. [We need] more action. That's obvious, because in recent years, we have been able to get a small grant for the elderly population. [With respect to the elderly] it's, sad, really sad. We have left our elderly minorities in the dark. This is the first year I've seen anything on research for the 50-plus; the 1997 AIDS Surveillance Report [is the first] to mention anything about the elderly population. So basically, what I'm saying is that we would like to see more action for our seniors. They are out there, and they do have HIV. And get the doctors a little bit more sensitive and also recognizing some of their ailments, because they go in there and are automatically diagnosed as having dementia, Alzheimer's, or they have some other type of disease, but no one looks into it and says, "Can this person



actually have HIV?" So, what I'm looking for is more into the population for the seniors, especially our minority seniors. We are located in the South Bronx, in which an alarming number of our seniors [have HIV or AIDS]. We have to teach them and have more of a bilingual type of thing for our community. We need to have those efforts out there. So, I'm just urging you to remember the elderly population and help us out so we can have an effective program running.

**Barbara Sullivan**

**Staten Island AIDS Task Force**

Good morning. I'm representing Robin Garber, Staten Island AIDS Task Force, who became a grandmother last weekend and couldn't be here. Robin asked me to make everyone aware of the Peer Training Institute, of which she is the coordinator. The Peer Training Institute is a New York City Department of Health-funded program that involves six agencies in four of the five boroughs, including Staten Island. On Staten Island, the population that we train to be peer educators are people with substance-use history in the correctional facility, Arthur Kill (that's on Staten Island) and in the Staten Island community. Of its HIV/AIDS-infected population, 63 percent of them got that way from injecting drug-use or being sexual partners of injecting drug-users. And yet we are the only one of the five boroughs that currently does not have a needle exchange program. I don't know that Robin wanted me to talk about this, but it occurred to me that we are being hosted by the agency [HHS] whose director didn't want federal funds to be used for needle exchange. Correct me if I'm wrong. So my agency and Staten Island University Hospital are now writing a waiver proposal to New York State to get a needle exchange program on Staten Island. We're coming up against strong opposition from people who don't understand that it doesn't increase drug use, no matter how much we tell them that the studies prove that. And the Peer Training Institute is addressing another end of that by taking people in recovery with a substance-use

history, sending them out to do street outreach after extensive training, and hopefully placing them as interns in agencies that need peer educators. They go through a six-month training program where they have a lot of didactic stuff from Cicatelli [Associates Training Center]. And then they go out into the community. But I'd like to send this message to Dr. Shalala, that we're suffering on Staten Island from injecting drug-use infection and we need needle exchange.

Response from Marsha Martin, Special Assistant to the Secretary, U.S. Department of Health and Human Services:

In response to the needle exchange question and challenge: I will take the message back to the [HHS] Secretary. I just want everyone in this audience to know and understand that the Department of Health and Human Services took the route which the Secretary will always take—and that is to look at the research and make the results of research available. The strategy the Secretary took was to try to keep the issue of harm reduction and the use of sterile injection equipment in the science/public health arena. And that's where we in the Department worked with it. From that experience, we in the Department were prepared to fund some demonstration programs that would have allowed us to take the science and the research to an application practice process. One half-hour before the Department was prepared to hold a press announcement, the White House determined that we could not use federal funds to support harm reduction programs that had anything to do with the exchange of clean injection equipment. I want to clarify—and I appreciate that you offered up that we could clarify this point—that the HHS Secretary, as a result of the work of her medical advisors and scientists from the National Institutes of Health, had made a determination that it was appropriate for the public health agency to fund, through demonstration programs, this approach. This decision was ruled out by the White House. That is a fact. So, if you have heard otherwise, perhaps you didn't understand the process we were going through and didn't really know how close we were. As a result of that, many of us were on the phone calling health departments and those who had already funded needle

exchange programs across the country, and the harm reduction coalitions and networks to express our concern and disappointment, and to let people know what had happened. We agreed to put the science out. We agreed to send the information to the states, which we did do, and we made packets available (in fact, we gave them to our Regional Directors as well), so that people would know the science that we used to come to our conclusion. They would have information about the health departments and the programs that were funded around the country, and people could then make decisions to use local dollars and state dollars to fund their programs, because we could not use federal dollars. We still have dollars in research. And there is no absolute ban at this point, if you will. But I want people to appreciate that the Department, as a public health agency, had made the determination that it [needle exchange] reduces HIV transmission and does not increase drug use. We were prepared to go forward, and we could not.

**Orlando Roman**

**Harm Reduction Coalition**

I totally understand Dr. Martin's position and, Dr. Goosby [Director, National HIV/AIDS Policy Office], you spoke like a regular-harm reductionist the whole way through your speech. You used a lot of words about engaging of substance users and people whose behavior patterns would put them at risk of contracting HIV or just taking care of them. You have used, respectfully, high risk and the review of statistics, and the lack of dialogue among African Americans and Latinos in the community and how that trickles down. You expressed it great. Behavior patterns versus the war on drugs: I wonder where it is that you're going to at this step? Now, you've put out the information about syringe exchange and how they work and so forth. O.K. Fine. We've got it down. These are wonderful, very intelligent tactics. And fine, that's just the way it is. People have to do what they have to do behind that. But behind the drug culture in itself and all the money that's used in the drug war, I wonder about where the administration waivers within the



two when it comes down to that. Because I think that's where the debate is—not just about giving out syringes, and not just about heroin use, but also about crack cocaine use, and the international global efforts around that and how those implicate things. I think that that's where we need to discuss things and how that affects us as communities as a whole. Where we have no real power over what is [introduced] into the community as far as drug addictions and how people are treated as humanely as they can be in regard to those issues—because if I don't have the ability to walk up to you and admit that I'm using substances and I have all these issues—that you may take my baby away, or you're a doctor who has a lot of prejudices and can't really treat me well...I wish I had time to keep going.

**Myron Gold**

**PWA (People with AIDS) Advisory Group**

Good morning. I'm a member of the PWA [Persons with AIDS] Advisory Group to the Planning Council, I'm chair of the Outreach Committee, and I'm also a member of the New York City HIV Planning Council. But I'm here this morning more importantly to talk about being a PWA over 50. I'm a 58-year-old gay male living with HIV and AIDS since December 1993. I've had a very rough struggle since I have been ill since the day I seroconverted. Many people in the community would call me old, elderly, or other words that society has for people over 50. It is time to realize that people over 50 are also useful and contributing members of our American way of life. Not knowing how to deal with people over 50, especially those who are chronically ill, the best solution suggested is to retire them to the nearest nursing home. I am here to say that I am 58, ill, but not ready for "pasture time." The impact of AIDS on the inclusive populations over 50—when I talk about populations over 50, I am talking about gay, straight, transgender, IV [intravenous drug] users, white, black, Hispanic, Latino, Asian Pacific Islanders, Native Americans—every population over 50 that is affected by HIV. It has been devastating. We are seeing epi-data indicating that 10 to 15 percent of AIDS cases are over 50, and yet this age group continues to be considered an "other" or "special"



population. When you realize that there are also long-time survivors who will be going into the over-50 group, we will see soon a swelling of percentages of people over 50 with HIV which will be incredible. Have people over 50 been included in clinical trials? Are there studies on how HIV affects people over 50? I have taken all HIV medications, and most have failed. I am dealing with severe arthritis, kidney stones, and heart changes due to protease inhibitors, fatigue, etc. No doctor can tell you what effect HIV has had on the aging process, other than to say that HIV tends to replicate faster in older people. What is the connection between HIV and aging? What is the connection between HIV medication and medication for illnesses that affect older people? Is anyone looking at this? We need these issues investigated. People over fifty in many cases are hiding for reasons of shame, denial, and embarrassment for the families. Yes, people over 50 do have sex. People over 50 do use drugs. And people over 50 get HIV and die. It is time for the government and medical people to start addressing this very critical issue. Thank you.

Chris Norwood

**Health Force: Women and Men Against AIDS, 718 AIDS Coalition**

I'm Director of the Health Force: Women and Men Against AIDS and Co-chair of the 718 AIDS Coalition. I'd like to really thank you for having this meeting this morning. I want to bring up two issues. First is the bias in AIDS funding. Over 70 percent of AIDS cases in New York City now are in the outer boroughs. The federal government has not met its oversight obligation to see that this money is properly distributed by case load in New York City. I will give three examples. Last year, after years of complaint, the HIV Planning Council finally conceded and voted to distribute Ryan White funds by high-need zip code. This was a directive of the Planning Council. It was openly ignored in distributing the funds. When the New York City Department of Health a few years ago used a special supplemental CDC [Centers for Disease Control] grant to set up peer projects, there were six peer projects. Seventy percent of these services went to Manhattan and not one peer

project went to Brooklyn, which has the largest amount of African Americans with AIDS in the City of New York. And although the majority of HIV-positive parolees are in the outer boroughs, all but one of New York State AIDS Institute grants for parolee services are contracted to Manhattan organizations. I would also like to bring up the perversion of Ryan White funds for the collection of statistics rather than for the delivery of services. The perversion of Ryan White money from providing vital services to collection and compilation of redundant statistics is staggering. It is not easy for the larger organizations, which actually have overhead money—and as you know, the cap on administrative costs for Ryan White funds is such that if you are a small organization without any other overhead, you are forbidden to use these funds to pay data personnel to collect the very statistics that are required as part of your program. The level of statistical collection is such as is not required for any other community-based funds. It is a level that is required for research and epidemiology and when it is required, it is paid for. These organizations are drowning in an insolvable dilemma. There cannot be this requirement both from MHRA [Medical and Health Research Association] for separate statistics and from HRSA [Health Resources and Services Administration] for other statistics, two financial reports and a demand and push that you collect all these statistics even on clients who aren't under Ryan White but may be Ryan White-eligible. This has to cease before these organizations drown.

**J. Edward Shaw**

**New York City HIV Health & Human Services Planning Council**

Good morning. I'm 57 years young. Living with AIDS for the past five years. I'm not here to represent the [HIV] Planning Council as such, but just as one of its 45 members of which there are 18 self-identified HIV-positive. Over the last five years, I've committed myself to AIDS activism. As a member of the Planning Council, I've recently been appointed Chair of the Housing Work Group, and the HOPWA [Housing Opportunities for People with AIDS] Advisory Committee. As such, I'm the "pitbull" that Dr. Primm spoke of—because I speak up, I speak out, and I speak

often, so that funds are directed appropriately to the communities in general but also toward the communities most infected. That includes the teens, the young adults, and the seniors as well. Just recently, at the Executive Committee meeting, I strongly suggested and recommended that the \$1.2 million from the Congressional Black Caucus initiative be directed toward the epi-data by zip codes, of which there was overwhelming support by the Executive Committee. I'm outraged that needle exchange programs are not yet funded, knowing full well that needle exchange decreases the transmission of HIV and AIDS, and I think it's time now that we do the right thing and begin to fund the appropriate programs. Thank you.

**Claire Griffin, LCSW**

**Life Net Center**

I'm a Licensed Clinical Social Worker in private practice. I'd like to thank Dr. Primm and Mr. Gold for acknowledging "bulldogs in the house" and others, because that's who I am. I'm here to raise the consciousness of the panel here today, and ask that you consider something that I often do not hear. I will start with a basic assumption. This is from a woman who is self-identified as an HIV-positive lesbian. She says, "we have a population of women not counted, with numbers of us already infected with the virus. I am one of them." She's incarcerated as well. We must learn to educate ourselves because due to our minority status and our society, women who sleep with other women exist in every community in this country, no less the world, but are invisible.

I am an invisible lesbian, standing before you today. I'm standing here to ask that when we talk about priority-setting—I'm also on the HIV Planning Council in New Jersey—when we talk about the group of women who are at-risk, we need to talk about [the fact that, particularly in African American and Latino communities] our numbers are rising and we are dying. We need to have more information with regard to "how do I stay protected, how do others who identify as myself stay protected?" We don't talk about women's sexual practices. The CDC's [Centers for



Disease Control] tools that they utilize to gather information from women are tools that are mostly geared towards men and heterosexual activity. There are two questions now on current documents, only two, that address women's activity. This is a start. I'm hopeful. Oftentimes, ad nauseam, I would hear that we don't have enough information. But we don't have enough information because we're not trying to get that information. I'd like to challenge the CDC to do something that's kind of on the side, which is, don't always look for your epidemiological studies to give you an idea of who is getting infected and who is at risk, because since the beginning of this epidemic, women have not been studied and our sexual practices have not been studied. I can't wait for data. I am dying, so I need to ask. There is consciousness to be raised. And please don't be afraid to say "lesbians" or "gay women." It's O.K. It's not offensive. "Bisexual" and "transgender" are not offensive. Thank you.

**M. Saida McLaughlin**

**Heals Program, Community Food Resource Center**

I can't state one organization, because I belong to the "People's Republic of Brooklyn." So for those of you who know me and those who don't, here's a taste. Pasadena, 1997: national. New York, New Jersey, 1998: states. Brooklyn, 1999: local. You're getting closer. Women and HIV have been fact-founded and information-gathered. But yet, we are still begging. Women-born, raised, transformed, and transgendered—are dying. The numbers show that ours are increasing dramatically, as sexual partners of all genders, as drug-using partners, through IVDU [intravenous drug use] and crack and alcohol. As mothers giving birth to infants, sometimes females. As women who are incarcerated and who will possibly be denied parole. And as the real markers due to "heterosexual" transmission. But yet we are underserved across the spectrum of life. The state of emergency in my community has \$156 million waiting. As of this Friday, some Black gay men in Louisiana will be deciding how to "divvy up" that money. [Congresswoman] Maxine Waters promised that the face of HIV and AIDS will be



involved in every step of the way to meet our needs. What is the status of that proposed dispersal of these funds? And how can we speed it up? When will we receive a just portion? Thank you very much.

**Sulma Marshall**

**BedStuy/Crown Heights HIV Network**

I'm from the [Bed Stuy/Crown Heights] HIV Network in Brooklyn, but I'm not here for them, but for me. It's my concern. I've been in the business since 1983 due to my brother, who died from AIDS in 1997, and I promised him then that I would learn everything I could possibly learn from that. I left a \$42,000 job to get my Bachelor's of Science degree in Community Health, and I did that. My question is, why can't we who are *affected* [by AIDS and HIV] be on the [New York City HIV Planning Council] PWA [People with AIDS] Advisory Board? Why? Because my brother went to his death and he had a question and I could not get into a meeting to ask his question. The thing was, is that everyone said, "you don't understand." I understood through my brother what he wanted to say, and his words couldn't be said because he couldn't get in there [to that meeting] because he was in the hospital. But I wasn't in the hospital. I want to know who passed the law that an affected brother or sister can not be on the board? That is my question. If anyone can answer me, I've got a couple of more seconds. Give it to me!

**Paula Santiago**

**Harm Reduction Coalition**

I want to thank HHS for being here today and giving us the opportunity to have this meeting. I am also the stupidest woman on earth. And I'll tell you why. When we want to go to war, we say "abracadabra" and money trickles down. When we want to go to the moon, we say "abracadabra" and money trickles down. When we want to, uh, I don't know, investigate what's happening in the Oval Office, we say "abracadabra" and the money trickles down. We don't have enough drug treatment

programs. We are screaming and we all know from the data that needle exchange works. Why can't we say "abracadabra" and the money can roll down? Why? Why can't we send our children the right message, that every life is worth saving? Thank you.

**Stewart Grossman**

**Prevention Café, Get Safe!, Mercer Street Friends**

I just came in from New Jersey last night. I did not bring the weather with me. I hope I don't take it home either. I'm a Prevention Case Manager for adolescents in Trenton, New Jersey. I also serve as Chair of the Incarcerated Populations Committee for the Community Planning Group. Everyone is talking about the problems that the year 2000 will bring. The next millennium actually begins in 2001 and the HIV pandemic will be going into the third decade. Today we are discussing the second generation and what we have lost and gained, and what there still is to do. During the course of the last 20 years, we have identified and addressed the needs of priority populations. For example, women, youth, men who have sex with men, and people of color. We must not forget that all these people are among the ranks of the incarcerated too. Incarcerated people have a unique disadvantage, but a possible advantage. They are at a disadvantage because all aspects of their lives are determined by corrections staff and parole officers. They are at an advantage for the very same reason. The advantage is, that for many, it may be the first time that they come into contact with doctors, nurses, or educators. Correctional facilities can do a lot to ensure that incarcerated people in their care understand about HIV transmission and how to protect themselves and others. For those already infected, they need to make sure that there is access to treatment and continuity once they're released. The good part is that we service a large part of the at-risk and infected populations in [correctional] facilities. The bad part is that we're not [done] doing it. For the next generation, it is my hope that more emphasis is given to incarcerated and newly released peoples. Let's make sure that they don't stay part of the third generation of the pandemic.

**John Chermack**

**New York City Hospice and Supportive Care AIDS Initiative**

I'm one of 18 self-identified HIV-positive members of the City's HIV Planning Council. The New York City Hospice and Supportive AIDS Care Initiative is a collaborative effort of nine of the City's home hospice and supportive care programs that came into being two years ago to address the severe underutilization of hospice care from persons who died from complications due to AIDS in New York.

Nationally, about 35 percent of those who die from complications due to AIDS receive their end-of-life care through a hospice program. [In] San Francisco [it] is nearly 68 percent, in New York City, a staggering 2.7 percent. The reasons for this are many. Hospice has been largely ignored, not only by people living with AIDS, but ignored by their social service providers, by their health-care providers, by the Planning Council, by the AIDS Institute, and pretty much everyone across the board. There's been a lack of awareness of what hospice programs are available, a gross misunderstanding of what hospice is, when it is appropriate, or how to access services. There's recently been a great emphasis on treatment and we're ignoring the people who continue to die. With hospice itself, there have to be restrictions that have traditionally proven to be barriers to care. There's been inadequate financing from Medicaid and other insurers. The daily reimbursement for Medicaid has proven to be inadequate to cover costly medications or to provide enough hours of home care to keep people in their homes. And the fact that there is Medicaid reimbursement available for hospice has effectively prevented most hospice programs from accessing Ryan White funds. Our program is looking to establish and promote a standard of care within hospice to outreach to the AIDS community and work for more equitable funding for hospice care.

**Lowell Hickman**

**Velez Associates, Washington, D.C.**

I've been around since 1983 as well, and I've seen many people come and go. I also



work with SAMHSA [Substance Abuse and Mental Health Services Administration], CDC [Centers for Disease Control], and HRSA [Health Resources and Services Administration], so I do know, first hand, that there is no communication. You try to get a memo out, it takes about three months if you have to get another department to sign off on it. In all of the CPG [Community Planning Group] meetings that I've attended, all of the organizations responding to AIDS meetings, all of the models that work meetings, no one addresses marijuana and youth. You don't go directly to a needle. You start somewhere. Why are they not addressing that start? You have high school meetings on Health Days. That does not do it. You have to address these youth with, "You need not do this while you're doing this." You have to give them examples. Health Day does not do it. You want someone to come to your booth. They're not going to come. Then you send people out there that they cannot identify with. This has been going on since 1983. I've seen too many people start off at marijuana and alcohol and move up to crack and needles, and still to this date, nothing is being done. [I am told] "We'll get back to you, Mr. Hickman." Well, when are you going to get back to Mr. Hickman? Why is this? No memos, nothing! What is it, the numbers of the increasing youth are not enough? What? What is it? I don't understand it, and I haven't understood it since 1983.

Jeff Birnbaum, M.D.

HEAT Clinic/Adolescent HIV Clinic

SUNY Downstate Medical Center/Kings County Hospital Center

I'm a physician and I work here on campus [at the SUNY Downstate Medical Center in Brooklyn] with HIV-infected adolescents. I've come here today to talk on behalf of the 125 adolescents who've come through my clinic over the last several years who are HIV positive. They are very disenfranchised with very little voice in the community at large. I think it's glaringly shameful that we have an absence of the issue of adolescents and HIV on today's agenda, and I'm really sorry that none of the speakers who came up here today mentioned this issue. Fifteen to twenty-four



year-olds in the CDC [Centers for Disease Control] data make up the most quickly growing population of new infections in the United States. Who are these 15 to 24 year olds? They're young people of color. They're sexual minority. They're disenfranchised youth. They're youth in the criminal justice system. I could go on and on, and if you give me more time I will. The issue of HIV and adolescents tends to get swallowed up by pediatric interests and as well by adult interests and everyone struggling for their numbers in their clinics. I think we need to have alternative service models and put adolescents at the forefront of our agenda. If we're not here to talk about adolescents, we're not going to even scratch the surface of this problem. If you want to give me \$50,000 to come up with something, sure I'll take it, I can do a lot of creative things with \$50,000, but that's not even going to scratch the surface.

**Charlie McCarron**

**Catholic Charities Health Systems, Inc.**

I'm the Administrator for AIDS Services for Long Island Catholic Charities. We've been doing AIDS services since 1986. The bulk of our client population is mentally ill chemical abusers with AIDS, many of whom are homeless and active substance abusers. I also serve on the Nassau/Suffolk HIV Planning Council and the Nassau County HIV Commission, and so besides my own agency's experiences, I bring the issues of a region that goes from the suburban/urban environments of Hempstead and Western Nassau to the growing numbers of infected migrant farmers, whom we're seeing on the East End of Long Island. It's not fun being homeless and infected with AIDS in a place like Corum, where you can literally end up sitting in the middle of the woods without any services. But today what I want to speak to and speak for are the dually diagnosed mentally ill chemical abusers. Against the health dangers that are caused by the fragmented and disjointed funding streams, and program parameters brought about by the divisions between agencies like New York State's OMH (Office of Mental Health) and OASAS (Office of Alcoholism

and Substance Abuse Services). My kids on Long Island live on the street, are dispensed protease inhibitors that require refrigeration. My kids are refused admission to psych inpatient units, either because of their active substance use or HIV diagnosis. Our county jail is becoming, for those of our clients who have serious mental illness, the one institution that "accepts" them and the jail is becoming the one safe environment for my kids, which should never happen. It's the only place they end up in. To resolve some of these issues may require what we in communities of faith might call a conversion experience. Substance abuse and mental health agencies and government regulatory bodies need to get over turf issues and pride and outdated bureaucratic structures, and treat the dually diagnosed as a whole and entire person with needs.

**Kathleen M. Nokes, Ph.D., R.N.**

**New York Association of HIV Over 50**

Hi. I'm a registered nurse, and this is Ed Shaw. We're speaking on behalf of the New York Association on HIV Over Fifty. In 1991, health and social service providers in New York City recognized that there were commonalities in the needs of older persons and those with HIV/AIDS. Since the CDC [Centers for Disease Control] statistics indicated that 10 percent of all persons with AIDS were over 50 years of age, the Association, formerly known as the Age and Aging Task Force, decided to direct its work toward persons over 50 who are living with HIV and AIDS. The New York Association currently consists of health and social service providers in the AIDS and aging fields, along with older persons directly affected by HIV/AIDS, either through their own infection or through their care-giving activities. Our ongoing activities include collaborating with New York State, not New York City—they don't seem to need our help—on the CDC-mandated PPG [Prevention Planning Group] to address prevention issues for older persons with HIV infection, offering educational presentations. We offer two seminars a year. The William F. Ryan [Community Health] Center has been assisting us to financially support these seminars, and our next seminar is tentatively scheduled for May 18 at Brooklyn

Hospital. [We are also] collecting data about HIV-related risk behaviors and our recent survey reports that people over 50 are putting themselves at risk. [Our activities also include] providing resource material and collaborating with the national group. Questions which we are frequently asked, but cannot answer and expect that the Department of Health and Human Services would be able to answer are: Since people with HIV are living longer, what plans are being made to address needs of HIV-infected people who are over the age of 50? How do prevention messages need to be tailored to appeal to middle-aged and older adults? The CDC has reported that persons over 50 are more likely to die within one month of their AIDS diagnosis. Why? How can HIV-related symptoms be differentiated from symptoms associated with aging? What percent of middle-aged and older adults have other co-morbidities in addition to HIV infection? Is the incidence of side-effects and more serious toxicities higher in middle-aged? We have had no funding and no staff support.

**Yollette Bonnet-Pierre**

**Brownsville Community Development Corporation**

**BMS Family Health Center**

I represent Brownsville Multi-Service Family Health Center. I just want to share Anna's passion because my problem is our prevention services in our communities. In reviewing the data, it has stated that Brownsville, for which the zip code is 11212, has more AIDS cases than Iowa and 11 other states combined. However, we have no prevention dollars to address that. We have [some] prevention dollars—I believe a small grant and Think Twice Program at Brookdale [University Hospital and Medical Center in Brooklyn]—to address youth. We also have a small program in the Greater Brownsville Youth Council. We know that prevention does work when we actually do it. We know that giving someone a condom at the corner is not going to change behavior. That's not what we call prevention. We know that continuity is needed. I have a program where we have a COBRA [case management] program and



within our COBRA program, we have one member of the family who is infected. Once that member of the family dies, we no longer service the family and they are at risk. We tell them, "I'm sorry, but we no longer can provide services for you." Now, meanwhile, we know they are going to come back to us six months later and now they're going to be positive, and that now we're going to have to address them. We need to stop doing business the way we've doing it, because it's not working. And I am so sick of knowing that I am a so-called "director" [and] that I have to do all the services in my clinic because we don't have the staff to do it. When my clients come to me and say, "Ms. Pierre, I don't have any place to go—I'm not positive, but I want to stay in the support group," I have to tell them, "Go back out there and catch HIV, and then you come back to me, and I'll be able to service you." I'm sick and tired of this, because I feel that I've taken these people under my wing, and if my funders knew that, that they would reprimand me. And I know that we need to say something, and I want to thank you for allowing us to have access to you so that we can call you when we don't have the consultants to write the best proposals so that our agencies can be picked. Thank you.

**Tokava Norville, T.C.**

**Project Resolve, Lesbian and Gay Community Services Center**

I'm somebody who has been living with HIV for 17 years. I don't take protease inhibitors or anything like that. I'm not saying that it's not good, but I just don't take it. There are quite a few things I wanted to hit upon, but the first thing that I think is important, and I heard someone else speak about it, is the young kids growing up. I know from myself, as a gay man, if there wasn't a gay and lesbian community center for me, I most definitely would have been dead. Now we have a big population out there of people who are invisible and they are the gay and lesbian population, and black people cannot forget that we are there. We are the uncles and aunts who keep the family together. We have a lot to contribute. Like they say God says, "If you don't use it, you lose it," and this is the population that we have to stop denying their existence. That's one thing. The other thing I wanted to talk about is



the drug problem and AIDS. You know, I'm not going to say that drugs are bad, because I believe in what God said. "It's what goes in you." It's not what goes in you that's bad, it's what comes out of you. I've seen plenty of people in 12-step programs who say, "I'm not going to take those protease inhibitors because I can smoke my crack and that will raise my T-cells<sup>1</sup>." You might snicker and laugh, but this is what they believe: "Why should I take something that's not going to get me high, that's going to have all these side effects, if I can take something that's going to get me high, take care of my T cells and everything else? You're not telling me anything." You know, they just did a thing on *60 Minutes* on what was going on in Geneva. If we are so interested in getting information out there to the world—we had a program right there, showing us that if you make it legal, and deal with it as a sickness, as an illness, it can be handled.

## Tokes Osubu

### East New York/Brownsville HW Care Network, Miracle Makers

I'm the Network Coordinator for East New York-Brownsville HIV Network, which is a Ryan White consortium. We have over 90 agencies based in the East New York/Brownsville region. That is the area that is nationally known as the epicenter of the epidemic. So, remember 11212. Now my issue has to do with, and we have heard a number of things not very complimentary about, the HIV Planning Council. I do *not* plan to change that for one minute. I have a problem with a body that makes decisions about where funding should go, but that does not represent the community where the epidemic is. Now, we have a big, big problem. That is a group of people who, oftentimes when you invite them to come to Brooklyn, say "Where is Brooklyn?" I mean. Two years ago, in 1997, we had about 33 CBOs [Community Based Organizations] funded under Ryan White. In 1998, about 23 of

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<sup>1</sup> Note: According to Dr. Eric Goosby of the National AIDS Policy Office, it is reasonable to think that the use of a sympathomimetic drug such as cocaine might result in an increase in T-cell counts through the mechanism of demargination of white cells. However, there is no evidence to support that this response is sustained nor that it has any impact on total CD4 T cell counts.

those were cut. Much of that funding was moved to Manhattan, to agencies that are supposed to serve my community, but do not have an office, do not have a site, cannot tell us how, cannot tell me how much money they got to service my community, and cannot tell me how many people they serve in my community. That also goes beyond those Brooklyn and Manhattan agencies and extends to HRSA [Health Resources and Service Administration]. HRSA has repeatedly, and I say repeatedly since April of last year, [failed] to give us figures about agencies funded in Manhattan to serve East New York/Brownsville. I'm challenging you to do something, and I dare you not to do anything.

**Amador Rivera**

**Discipleship Outreach Ministry**

I work with Discipleship Outreach Ministry, Incorporated. I'm a Peer Educator. I'm a Vietnam-era veteran. I have been infected with the AIDS virus for over 10 years, and I'm tired of taking this medication. I'm also disgusted at pharmaceutical companies, the FDA [Food and Drug Administration], and everyone else and their mother telling me that I have to take these medications and that it's covered by my medical plan. There are alternative treatments out there, holistic treatments—why can't they be covered by medical insurance, HMOs [health maintenance organizations], and Medicaid? I'm the one who has to suffer daily taking this medication, which makes me sick. I know there's a better way. Like I say, for over 10 years I've been taking this medication. Yes, it's been helping me, in one way. But it's also killing me in another. And I want you to tell me, "Who are you to tell me what kind of medication I should take?"

**Carol Horowitz**

**Brooklyn Legal Services Corporation**

I supervise HIV/AIDS Legal Work for Brooklyn Legal Services Corporation. We serve the communities of East New York, Brownsville, Bedford Stuyvesant, Flatbush, and Bushwick in Brooklyn, probably the epicenter of the epidemic for

African Americans in North America. I just want to give you two examples of what the face of AIDS looks like to me in my practice and to others doing HIV legal work in these communities. About three months ago, I was in family court, which is part of my job, to represent parents and future caretakers living with HIV and AIDS for children to make future care arrangements. I had about 18 petitions for guardianship and standby guardianship. And as I got to the last one, my client was a 12-year-old with full-blown AIDS, whose only remaining relative had come up from South Carolina and was a second cousin. The judge said to me, "Counselor, is there no one else? No immediate family member?" And I said, "Judge, both this child's mother and father, both sets of grandparents, the mother and the father's siblings, and any other close relatives that we could determine have all died." Two, only two, died of non-HIV related illness. The rest died of HIV. The second case I want to tell you about is a grandmother who is now caring for 14 grandchildren, eight of whom are AIDS orphans. This grandmother has struggled and struggled and struggled to keep this family together, and we have struggled along with her. Yesterday, she was called down to the welfare office for a face-to-face certification, and while she was there, her identification was taken from her, she was told that there is no way she could be caring for this many children, she was committing fraud, and she would be arrested. It was only when she called us hysterical that we were able to go down and prevent this from taking place or restore her benefits. This is the face of AIDS. This is what we are facing in Brooklyn, New York, today. We need resources. We don't have them. Please try to get us some.

**Marie Houanche**

**Schachne Institute of Brookdale Hospital**

"Bonjour," "buenos dias," "good morning." My name is Marie Houanche, better known as the singing nurse, and I'm representing the Haitian community. There is a need for a lot of bilingual information. There's a lot in Spanish. I've done a lot of translation in getting the word out to the Haitian community. There are a lot of



Haitians who are here that don't understand English at all, and there's a need to get the information to them in their own native language. It's very important, because these days, a lot of people think there are different cures. There's different cures besides the medications. A lot of people talk about the holistic aspect. Herbal medicine is very important, which a lot of the hospitals and other centers are not getting the information about the herbal lies that are out there. Nutrition. One of the gentlemen talked about nutrition, and also exercise is very important as opposed to medication. I know the "pharm reps" [pharmaceutical company representatives] are out there pushing that medication, but also we have to give the information. I'm here not to talk about prevention. I'm here to give out education. I'm a nurse clinician and I believe in education. There's a rise in the teen population and also in the elderly. I work with the teen population, and I think the most important thing to get the information out is through the media. All these rappers, all these singers, I do a lot of fund-raising in the community and the money that I get from the fund-raising, I do a bilingual program on the radio giving out the information to people. I'm saying, "Open your doors, and give the information to the bilingual community, to Haitians, to people who don't know the language give [them information] in their language, and let's stop this disease, because it could be stopped if we want it to stop."

**Matt Hamilton**

**Mayor's Office of AIDS Policy Coordination**

On behalf of the State and the City, I'd really like to thank you very much for being here. I think you can tell that New York is not a quiet place. People are more than willing to put their issues on the table. I think it's really important that you hear the issues, and I hope that you will come back, that you won't make this a one-time shot, that you will come back and respond to people's concerns. There are a lot of issues, obviously, that need to be worked on at the city, state, and federal levels. I'd like to talk about one of them, and that is continuum of care, which we've all talked about a lot. But I think there needs to be a focus to that and I'd like to make this



suggestion: You start with the CDC (Centers for Disease Control) and SAMHSA [Substance Abuse and Mental Health Services Administration]. Those are the two big agencies that HRSA[Health Resources and Services Administration]—and I think I'm talking primarily to you, but quite frankly, specifically to the CDC, and specifically to SAMHSA—that they come to the table ready to deal and ready to play. And that would be my suggestion for a focus in terms of how to move the process forward with the folks that we're dealing with here in New York. But my primary purpose is to say thank you very, very much for being here, and I do hope you come back.

**Lorna Fairweather**

**Caribbean Women's Health Association**

Hello and good morning. I work with a group called Caribbean Women's Health Association, within walking distance from this institution [SUNY Downstate Medical Center in East Flatbush, Brooklyn]. I stand here this morning because I want to talk about two main areas that need focus. One, the committee, when you talk about funding, really needs to look at the model that was used in determining the funding for the 704 cycle [a referral to the CDC's funding announcement #704, which provided funding directly to community-based organizations to deliver HIV prevention services]. That was an abomination to those of us here in Brooklyn, based on the numbers. To have 12 organizations who sent in applications and not be funded was a clear indication that that process didn't work for us. We can take care of [our programs] when the money gets to us. The track record speaks for itself, for the people who came to the mat this morning. We can do the work. What we need to do is to guarantee that the process that is determining on the other side—who is reviewing our proposals? Who is sitting at the table and determining the dollars coming into our community? We need more input with Suki [Suki Ports, a community activist mentioned in Dr. Primm's speech], we need more input in terms of Dr. Primm. [We need to participate] in that process to determine how we

get the dollars in Brooklyn in particular. Another area that is very important for us is the field of health prevention. About five years ago, I made a recommendation to Dr. Helene Gayle [Director of the CDC Office of HIV, Sexually Transmitted Diseases, and Tuberculosis] in Atlanta, because as a CBO [community-based organization], Caribbean's Women's Health got direct funding from CDC, and we went in the mix twice and we were successful in two national competitions to get funding. Here we had a situation where we had research given to SUNY, research given to Caribbean Women's Health Association. We can look through both our windows and see each other's buildings. However, the marriage between the researchers and prevention needs to happen, as was mentioned earlier. We do not have enough dollars to track our prevention effort as effectively as we could. So that's a model that I'm inviting you to look at.

**Sandra Estepa**

**U.S. Department of Health and Human Services**

Thank you very much. I do appreciate, as do all the panelists do here, that there is room for passion, for commitment, for frustration, for anger, and for partnership, and it is only through efforts like this that we'll be able to move this ahead and address these issues.

**-End, Public Comment Period-**

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# **WORKGROUPS**

**Discussion, Comment, and  
Recommendations**





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## **Northeast & Caribbean Region**

### **HHS Community Meeting on HIV and AIDS:**

#### **Confronting the Second Generation of the Epidemic**

## **Workgroups**

### **Discussion, Comment, and Recommendations**

Following lunch, the conference broke into individual workgroups. There were six workgroups in all; each covered a different set of topics and each was charged with developing recommendations in support of the goals of the conference. All workgroups adhered to the same format: presentations from speakers representing federal agencies that either fund or regulate aspects of the workgroups' topics, followed by an open discussion period. Facilitators moderated the discussion and wrote down recommendations on flip charts as they emerged from the give and take. Although each workgroup asked for volunteers to take notes, not all workgroups submitted notes at the end of their sessions. Back-up tape recorders were available in each workgroup room. However, because the rooms were not miked and the audio quality varied from workgroup to workgroup, not all questions/comments were audible. The recommendations from each workgroup—as turned in by the workgroups on their flip chart worksheets—are summarized here, and a review of each workgroup's discussion, taken from the notes and audio tapes, follows in the subsequent workgroup sections.

Because of adverse weather, there were several substitutions for scheduled speakers. The final plenary session, which was to have reviewed the recommendations, was canceled to facilitate travel home.



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## **Northeast & Caribbean Region**

### **HHS Community Meeting on HIV and AIDS:**

**Confronting the Second Generation of the Epidemic**

## **Workgroups**

### **Workgroup A: HIV/AIDS Care Children and Families**

#### **Speakers:**

**Barbara Andrews, Administration for Children and Families, Northeast & Caribbean Region, Douglas Morgan, Health Resources and Services Administration**

#### **Facilitator:**

**Roberta Holder-Mosley, Health Resources and Services Administration, New York Field Office**

In brief: This workgroup reviewed the Ryan White CARE Act and HIV/AIDS issues that impact children and families. The two speakers were Barbara Andrews from the Administration for Children and Families (ACF), Northeast & Caribbean Region, and Douglas Morgan of HRSA's HIV/AIDS Bureau, who had been one of the panelists in the morning session. Ms. Andrews provided an overview of ACF programs. Except for its Abandoned Infant Assistance program, ACF has no AIDS/HIV-focused programs. However, the agency does serve many children, youth, and families who are infected or affected by HIV and AIDS. Mr. Morgan reviewed funding under Title I and Title II of the CARE Act. He explained that entitlement funds are granted to state and city agencies to distribute and administer and are not given directly to community-based organizations (CBOs). Because of this, responsibility for equitable distribution is largely left to the recipient agencies, although a Planning Council must be established that is representative of the epidemic in the funded area. Mr. Morgan also discussed the Congressional Black Caucus Initiative, noting that requests for proposals (RFPs) should be released sometime in the spring of 1999.

Issues cited by workgroup participants included problems with Planning Councils and/or grantee agencies; inequities in the distribution process; the limited ability of CBOs to hire personnel to prepare grants and collect required data; the need for medications for children; and funding for the outer areas of Region II, such as the Virgin Islands and Puerto Rico.

The presentations of the speakers, and the ensuing discussions are presented more fully below. (Note: these are edited, both because of space limitations and because some of the discussion was inaudible on the tape. In the discussion section "Q" indicates comments from workgroup participants; "A" indicates feedback from speakers.)

**Speaker: Barbara Andrews, Administration for Children and Families,  
Department of Health and Human Services, Northeast & Caribbean Region**

As the external affairs officer for Region II, Ms. Andrews serves on a number of health-related task forces and partners with other agencies. She described ACF as “the human services part” of Health and Human Services. Its mission is to sponsor programs that promote economic and social well-being, through activities and initiatives that actively support child, youth, and family services. Examples of two ACF programs are Head Start and Child Support Enforcement. ACF also sponsors programs for child care, welfare reform, child welfare, developmental disabilities, and runaway and homeless youth. “You could say that our programs not only involve financial assistance, but also social services programming,” Ms. Andrews explained.

What do these programs have to do with HIV and AIDS? ACF programs serve parents, children with HIV and AIDS, and children who may not have HIV infection but cannot escape the hardships of this disease caused by infected parents, siblings, or caregivers. Examples include child-care services, adoption certificates, and cases where children are abandoned. So although its programs are not dedicated to the HIV/AIDS population, the services ACF sponsors do help vulnerable children, youth, and families, and other populations such as the homeless. ACF also provides technical assistance and support to providers through clearinghouses, research, and demonstration projects, as well as funding to local and state organizations.

Other examples of what ACF does include assisting children who have been abandoned in hospitals, communicating with children and parents, helping with assistance programs, and providing transitional program funding. While HIV/AIDS is not necessarily a discrete ACF priority in and of itself, Ms. Andrews explained, ACF does provide many services for those with HIV/AIDS. Head Start for example, does not specifically fund services for these children, but it is part of the ACF service base. “You may not associate many of our income-support programs with HIV or AIDS,” she said. “But when you are dealing with a population that is ill, you need to be concerned about who is going to support the children and families.” As part of her presentation, Ms. Andrews distributed ACF program materials to participants.



**Speaker: Douglas Morgan, Director, Division of Service Systems,  
HIV/AIDS Bureau, Health Resources and Services Administration**

Mr. Morgan discussed the Ryan White CARE Act and the Congressional Black Caucus Act initiative. HRSA's Service Systems Division administers several titles of the CARE Act under which grants are provided to cities and counties. This means the division's relationships are with other levels of government, i.e., the people who sign the application forms. There is no direct relationship with subcontractors. However, Mr. Morgan said that he intended to respond to concerns raised during the Plenary Session about exclusion and inadequate representation on New York City's HIV Planning Council. He indicated that he planned to meet with the grantee for New York City (the New York City Department of Health and the Office of the Mayor) to examine these concerns.

Mr. Morgan discussed Planning Councils and how they should be structured. Under the CARE Act, entitlements are granted to cities, to be administered by health departments. The CARE Act specifies that a Planning Council must be established by the mayor and that it must be representative of the epidemic in that area. However, it is not up to the Planning Council to set priorities or identify service needs; rather, it must develop a comprehensive health plan for the area. It also has responsibility for monitoring the effectiveness of the grantee in distributing funding. The Planning Council does not have and should not play a role in who gets funded. It is left to the grantee to establish a fair and equitable process for distributing dollars that go to organizations and programs to carry out the mandates of the Council. A distinction that must be understood, Mr. Morgan cautioned, is that the grantee is the city agency that applies for the grant, while the mayor appoints the Planning Council. "We want CARE Act dollars go to providers of services to people who have HIV and AIDS infection," he said.

Mr. Morgan also discussed the Congressional Black Congress (CBC) initiative. He went on to say that CBC funds totaling \$12 million in Fiscal Year 99 were appropriated to the Ryan White CARE Act Titles as follows: \$5 million supplemental to Title I; \$3 million for planning grants under Title III; \$2 million for Historically Black Colleges and Universities under the AETC (AIDS Educations and Training Centers)

appropriated to the Ryan White CARE Act Titles as follows: \$5 million supplemental to Title I; \$3 million for planning grants under Title III; \$2 million for Historically Black Colleges and Universities under the AETC (AIDS Educations and Training Centers) program; and \$2 million for programs for adolescents, children, and women under Title IV. Mr. Morgan discussed potential time lines for receipt of proposals for these funds.

**Discussion of Issues: participant questions and comments ("Q") and speaker responses ("A").**

Q     What happens if the money does not follow where the data indicates that there is the greatest need? What if the Planning Council doesn't ensure that that happens? What sanctions do you have at your level?

A     [Morgan] We can ask the grantee what processes they have in place, and review them to ensure they were fair and objective. If in fact the process was fair and allowed all who could have played the game to do so equitably, then we would say it appears as if our threshold has been met. In cases where communities or groups feel that the process wasn't upheld, we can ask that the grantee mediate those disputes. If after mediation, people still have concerns, we can repeat the first two steps again. However, keep in mind that there will be times in the process when an organization just doesn't make it.

One of the things I've learned is that the ability of an agency to successfully compete for funding, whether at the federal level or state level, depends on the ability to write a good grant. You need to clearly articulate, in a way that the reader can understand, what you want to do and how you propose to do it with the dollars you are trying to get. It sounds simple, but I will tell you I have read applications from people who could not clearly tell me what their vision is.

Another problem is the issue of infrastructure and capacity. Unfortunately, given the way the CARE Act statute is written, it is not clear whether CARE Act funds can be used to build infrastructure—that is, to hire

staff to carry out the mission while also running the agency.

Q What if the Planning Council clearly articulates priorities, but the grantee privatizes the allocation process and sets up a standard for reviewing proposals which, when viewed in context of what the Planning Council wanted to happen with those funds, is irrational? It was “fair and objective” in that they scored the proposals. But they added up the scores without any concern or consideration about geographic areas or funding areas of high need. Anyone can “design a process” to review proposals that is supposedly fair and objective, but in no way, shape, or form does this apply to what the priorities are or where the funding goes. That’s what we’re looking at in New York City. That’s why a lot of people are very frustrated.

A [Morgan] To be blunt, we’ve heard your frustration. We’ve had numerous discussions with the grantee. And we will continue to have those discussions with the grantee based on some of the conversations I’ve heard both this morning and this afternoon.

Q Could you share with us the sanctions that are authorized by your agency at HHS and Congress?

A [Morgan] If conditions are not met, we can not release the funds to the grantees. If a grantee is not meeting the requirement of the law, we would have to determine whether or not we can identify a different grantee.

Q One of our biggest dilemmas is that different agencies want information in different ways. We don’t have the manpower or the computers to do this, since we’re an agency without a lot of money and it takes up clinicians’ time to provide all this data.

A [Morgan] Part of the reason for that is that we get asked questions about the impact of CARE Act dollars, who has benefitted, and what is the cost effectiveness. These questions come from a variety of sources—for example, Congress, the Office of Management and Budget, and the HHS Secretary’s



Office. We are looking at how we can make data requests consistent across Titles. For example, we are working with the CDC so that it collects surveillance information from cities and states using a very specific format, and we are trying to make sure our program's Request for Information doesn't conflict with the CDC's format. We understand that, yes, it does cost money to prepare these statements and support the evaluation.

You should also know that the way the CARE Act is currently written, there is a 5 percent administrative cap that the grantee imposes on subcontractors.

Q Can you explain administrative cap?

A [Morgan] The administrative cap means that no more than 5 percent of the total grant award can be used for administrative functions. That includes reporting data to us and preparing grants. Now, this is not consistent across all Titles. In Title I, it's very clear that only 5 percent can be used for administration. There is no allowance for planning. Under Title II, however, states are given 10 percent for administrative costs, and another 5 percent for planning. We have been considering whether or not to make an additional allowance for evaluation purposes, so that grantees can demonstrate that they are doing exactly what they said they would be doing.

Q What's going to be done with the funds to the Black colleges and medical schools?

A [Morgan] The \$2 million that HRSA has for AIDS Education Training Centers will go to Historically Black Colleges and Universities (HBCUs) that provide clinical training. We have not yet written the guidelines on that.

Q I have a question about ADAP (AIDS Drug Assistance Program). Who oversees the formulary? I work for New York City's foster care agency and we have kids in care who are positive who need treatment. It's very difficult for our foster



care agencies to provide proper treatment when certain drugs are not included in the formulary. Who is responsible for broadening the scope of drugs available through the ADAP formulary, and how can we get progressive, more current treatments for HIV infection into the formulary?

A [Morgan] The individual states and territories are the ones who receive the ADAP set-aside, and they are responsible for establishing the criteria for those who participate in the state ADAP programs. They should have a process in place to accept the guidance of clinicians to decide which drugs get on the ADAP program. The language of the act clearly says that these have to be FDA-approved drugs that address antiretroviral treatment or opportunistic infections. There may be some drugs over-the-counter drugs, alternative therapies, herbal remedies that simply would not be eligible under the current statutory restrictions. Some states with limited resources may not cover all the drugs that are available. The formulary available through Medicaid is probably greater than with ADAP.

Q In the monies of the \$156 million and \$22 million allocated for SAMHSA (Substance Abuse and Mental Health Services Administration), I saw no money allocated to mental health services. That struck me as strange, because of all the problems encountered by those with HIV infection and AIDS. I'm also concerned about Region II extending to the Virgin Islands and Puerto Rico. In the Virgin Islands, there is a waiting list for people to be on combination therapies. The money is just not there. What are we doing about that issue?

A [Morgan] I can't comment on why that distribution is the way it is, nor do I know the process and how SAMHSA will deal with that. on the Virgin Islands question, we have been very concerned about the Virgin Island response for some time, both from an infrastructure perspective, in the sense that there are limited clinical resources available on the islands, and from a clinical perspective, as it relates to the clinical skills of care providers. Up until this year, because of the way the CARE Act was written, neither the Virgin Islands or Guam

received AIDS Drug Assistance Program (ADAP) money. We knew we had to fix that, so this year the Virgin Islands will receive funding from ADAP in addition to their Title II funding. HRSA and the CDC are jointly looking at developing an action plan to increase capacity within the Virgin Islands. We have long had prevention concerns and care concerns, and these cannot be addressed adequately unless CDC and HRSA work jointly on this.

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## **Recommendations**

Workgroup A identified its top three major priorities as: 1) distribution of money, including oversight of the Planning Councils; 2) children's/family services, and 3) administrative processes. On the worksheets submitted, it grouped its recommendations into six different categories:

### **Distribution of money:**

- Funding should go to where the greatest need is. HRSA should help community-based organizations develop grantwriting expertise, infrastructure, and capacity building.
- HRSA should help to ensure equity in distribution of funding.
- HRSA should develop procedures to correct the distribution process.
- There should be sanctions where necessary to correct the distribution process.

### **Services to children/adolescents and caregivers' families:**

- Foster children's and adolescents' access to care. Formularies for these groups should be sensitive to children's needs. Who is responsible for expanding the formulary?
- Increase access to mental health services.
- Provide services to children of affected families.
- Expand medication options for adolescents and children.
- NHSC (National Health Service Corps) providers who serve designated underserved areas and are appropriately trained to provide care for HIV/AIDS patients should be made available to the U.S. Virgin Islands.
- Mental health services should be made available to children orphaned by AIDS.
- Support, in the form of both mental health services and fiscal support, should be available to caregivers and the extended families of infected and affected children.
- Respite care should be available for caregivers of infected and affected children.
- Services should be available for children of incarcerated HIV-positive persons.

- Clinical trials should address the following needs: clinical trials for children; education for caregivers; access, availability, capacity. Getting the trials to the patient is another issue.

#### Administrative processes:

- Deadlines for RFPs (requests for proposals) and applications should be widely disseminated.
- Because data collection can be difficult due to lack of available resources, data elements should be consolidated so that more time can be spent with patient care.
- Feedback to project officers from grantees should be used to revise how care is provided (new methodology) or who receives care under grant program.

#### Substance Abuse Funding:

- Increase access to mental health services.
- There should be adequate funding for substance abuse prevention programs (SAMHSA).

#### U.S. Virgin Islands and Puerto Rico:

- The U.S. Virgin Islands and Puerto Rico have insufficient money for treatment; additional funding should be available in this part of Region II.

#### Prenatal care:

- Case identification for women who have not received prenatal care.





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## **Northeast & Caribbean Region**

### **HHS Community Meeting on HIV and AIDS:**

**Confronting the Second Generation of the Epidemic**

## **Workgroups**

### **Workgroup B: HIV Prevention and Education Women and HIV/AIDS**

#### **Speakers:**

**Samuel Taveras, MPH, Centers for Disease Control and Prevention**

**Sandra Estepa, Public Health Service, Office on Women's Health, Region II**

#### **Facilitator:**

**Dorothy Gunter, Centers for Disease Control and Prevention**

In brief: This workgroup reviewed HIV issues and strategies specific to women, as well as how federal agencies can improve services to individuals, communities, and agencies. The first speaker was Samuel Taveras, who works for the Division of HIV/AIDS Intervention, Research, and Support at the Centers for Disease Control and Prevention as a teamleader for the National Leadership and Technology Assistance Team. He focused on how the CDC can help community groups with infrastructure and other technical assistance needs. The second speaker was Sandra Estepa, consultant for the Office of Women's Health for Region II of HHS. She emphasized that programs for women need to be integrated into federal, state, and local government planning. They need to embrace a comprehensive continuum of care that addresses women's needs across the life cycle and throughout the different stages of their HIV illness. The speakers also identified resources—websites, newsletters, satellite broadcasts, and upcoming meetings—that would be of interest to workgroup participants.

Participants raised a broad range of issues, including funding needs of small agencies, HIV prevention for women in prison, Planning Councils that fail to be representative, inequitable distribution of funding, availability of woman-specific prevention information, difficulties caused by HMO case management, and HIV prevention needs of adolescents.

The presentations of the speakers, and the ensuing discussions are presented more fully below. (Note: these are edited, both because of space limitations and because some of the discussion was inaudible on the tape. In the discussion section "Q" indicates comments from workgroup participants; "A" indicates feedback from speakers.)

**Speaker: Samuel Taveras, M.P.H., Centers for Disease Control and Prevention, Division of HIV/AIDS Prevention, Research and Support**

Mr. Taveras began his presentation by giving workgroup participants his telephone number (404-639-5241) and email address (cdc.gov). He described himself as a teamleader who works on program policy development. "I talk to communities, I hear from the communities, and I work with national and regional minority organizations and their technical assistance programs," he said. "I also work with grass roots organizations, respond to congressional inquiries, and most importantly, I try to influence policies and programs at the CDC." He said that he looks to initiate dialogues that will allow him to understand more than the obvious and told workgroup participants that their input was very important: "Although you may think that it may not influence us, it really does."

Mr. Taveras cited as an example the comments from the Plenary Session on funding not following the epidemic in New York City. "In the past, we've looked at New York City as a total block," he explained. "If we break that down, we may see that organizations in Brooklyn need to be given a higher priority in consideration for funding than in Manhattan. That sort of suggestion process is not in our consciousness. We were not aware, or really thinking about it in that way. So that's something that I'm going to bring back to the CDC."

The Centers for Disease Control funds 21 national regional minority organizations. One of the responsibilities of Mr. Taveras' division is to review and evaluate the technical assistance needs of HIV prevention programs. On another front, his division is about to inaugurate a program that will help community-based organizations by providing training on behavioral science, grant management, CBO administration, prevention, and other such issues. During the discussion, Mr. Taveras pointed out that his division, as part of its recognition of the importance of computer technology, is committed to providing lap top computers to all funded community organizations. He stressed that another priority is to get the newly approved funding out to communities as soon as possible. His division will be helping to develop the language and details of the RFPs.

**Speaker: Sandra Estepa, Public Health Service Region II, Office on Women's Health**

Ms. Estepa provided an overview of health issues relating to women and HIV/AIDS, noting that on a national level, the Office on Women's Health has been working with members of the Secretary's staff to form workgroups that will enhance advocacy efforts and help develop solutions for the problems that affect women. A Secretary's Work Group on Women and HIV/AIDS, consisting of representatives from each of the HHS agencies, has been formed to meet, share information, and coordinate initiatives. A second, external, body has been formed called the Collaborative Workgroup on HIV/AIDS and Women. Its members come from across the country and include women living with HIV, community activists, and representatives of community-based organizations that work with women on HIV issues. Cecilia Guiterrez and Fran Page from the Office of Women's Health have been coordinating this effort. Their phone number at the Central Office in Washington, D.C., is 202-690-7650.

Ms. Estepa distributed a list of HHS agency websites and the website address for the National Women's Health Information Center, which has links to all of the offices on women's health within the various HHS agencies. She also noted the availability of fact sheets that review each federal agency and the HIV/AIDS programs under their domains. Ms. Estepa described her role as one of forming partnerships. Although she staffs a one-woman office in Region II, she is available for consultation and can be reached at 212-264-4628.

In September 1998, the Office of Women's Health held the Women and HIV Summit, which brought together organizations and advocates in New York and New Jersey to review women's issues and discuss how the epidemic is affecting women with those who work on the frontlines. In response to questions about follow-up from that meeting, Ms. Estepa advised that a document compiled by the consultant Cicatelli Associates would shortly be in print and available for distribution.

"We know a lot about the course of this epidemic," said Ms. Estepa. "We know it's not affecting all women. We know it is disproportionately affecting women of color. We know that the issue of substance-abusing women with HIV is a critical problem, as is that of women immigrants and HIV. We also know that there is a whole array of



other issues. We need to look at integrated approaches.”

**Discussion of Issues: participant questions and comments (“Q”) and speaker responses (“A”).**

Q As far as the community based organizations that receive funding, does size have anything to do with it, or the community that we serve? Do I have a chance to be funded?

A In terms of eligibility, we’ll be looking for organizations that are minority-run in communities of color. There should be opportunities for outreach.

Q I am the family director of Life Network Center, which is my private practice. This is a mental health service organization that provides therapy and counseling to individual families and couples. I also do professional staff training and I’m an HIV/AIDS educator. The Life Network Center started in New York. It is now located in New Jersey, but it still services the City of New York as well as the State of New Jersey. My question is similar to that of my colleague’s. I am a party of one right now, and HMOs have made my life miserable. I can’t afford a 501-C-3, with its paperwork and required documentation. What am I do? I need funding now. In New Jersey, the CDC is wedded to the New Jersey State Department of Health. There are a lot of people who are in need of services who don’t get served. The money continues to go to the same organizations. I live in Hudson County. We have limited services geared specifically to women. I need somebody to talk to me, and to others like me who are trying to do what we can at the grass roots level. We need a road in. We need you to sometimes disengage yourself from the New Jersey State Department of Health, because your money does not come to us. And you need to know that.

Q: I think it’s atrocious that in a city as unique as New York there is no staff to address the issues of HIV and AIDS. We have to look at changing government’s perspective and government attitude. Programs should be where the epidemic is.



Q: We have the education. We have the prevention and planning tools to see what's going on in the community. We're getting the information, but yet we haven't been putting out the resources. It's not happening.

Q The same is thing is happening in New Jersey. The State Department of Health in New Jersey limits our abilities to do more. That's why I made the comment earlier about why the CDC should consider distancing itself on some things. Because once the money leaves the federal government and goes to the state, it's anybody's ball game. As long as politics stays connected to all of this process, those of us at the bottom still don't get anything. That's why I'm so happy the sister [in the Plenary Session] said "abracadabra"—we really need to practice that.

Q I was part of the HIV Women's Summit in September of 1998, and I was also part of the planning process. Where is all this now leading in terms of women and prison? Women and the forfeiture system? What happens to them? We need more data on that, and we also need to look at what happens to women while they're doing time and how their families are affected.

A We have the tools, we have the planning groups. What is the stumbling block? When you say "government" what about that do you believe is causing the problem?

Q I work for public government. I'm a grants person. I was on the local Planning Council for Ryan White monies in Hudson County. And the same thing that happens on the federal level happens on a local level. It's all about power and control. Who has the money? Who has the power? They've got the control. I won't even go back to the HIV Planning Council, even though I am a member of the power group, because they just shut me up. When you put your requirements in about the make-up of your Planning Council, it's still the big people who are in charge. The person in charge in the Hudson Council HIV Planning Council is also the head of welfare for the county. The same woman

[whose agency] takes women off welfare using sting operations is the same power that's the head of the Council. You [in federal agencies] when you review these things, you just see the names, and say "O.K. You've hit the African American community. You've hit the Latino community. We've done our job!"

You've got to start making requirements that are real. Even though you're not allowed to spend federal funds on needle exchange, you should require anyone who accepts federal funds to have a needle exchange program, or they don't get funding. This is a recommendation.

Q We sit and talk about issues. We know the issues. We live with the issues. Some of us providing services mirror our clients. That's the reality. We don't take into consideration, "What do I need when I work with a woman?" I went out with needle exchange the other day. I had to go home to bed at five in the afternoon because I was sitting on the waterfront for three hours. I finally decided I can't send peers out to do needle exchange in the winter when it is 10 degrees and expect them to do something that I can't do. That's in the way. So you see on some levels, an assessment has to be done of the agency or the provider. You want to have quality assurance, I don't know exactly what to call it.

Q I work in East New York/Brownsville, and within that community, 704 [CDC funding through program announcement #704] has been taken away. Twenty three of our programs have been taken away and given to Manhattan. As you know, managed care has backed us up into a corner. Sometimes we don't have money to pinch back. Clients come to us and in the midst of providing care, trying to survive, we have to write proposals. We spend the time and the hours—two to three o'clock in the morning, 24 hours, writing these proposals, getting them to the place that they need to go, to find out—"Sorry!" I don't know what else to do. We don't have the money to pay for this [grantwriters]. We're just surviving to pay staff. As I pointed out earlier, we have a support group. When friends of clients want to attend, sometimes we allow them to sit in, and they say, "Can I have that too?" And we say, "I can't serve you." So we need prevention case management for clients. And though we want to do it, we don't

have the money to do it.

Q I am a professional staff trainer and an HIV/AIDS educator, and I keep hearing the new word that everyone is now comfortable with: "cultural competency." However, when I approach programs that have been mandated to be "culturally competent" to come into compliance with their new grants, I get told, "We don't have the money, we can't afford the training." I don't understand that, because I keep hearing about money being available and programs being funded. Yet there's no money to receive training. Also, prevention dollars continue to be the first thing cut—but when you come before us in a forum like today, the first thing you want to hear from us is about what can we do in terms of prevention.

Q The number of the HIV Resource Center is 212-693-0995. I would like to encourage each manager to assign one person in your organization to be the information retrieval person. You do not have to be a librarian or have a librarian on your staff, but you should have an information person to get in touch with us.

A [Taveras] There is a directory for national and regional minority organizations. It provides information on who they are, where they're located, what their activities are, how they may be contacted. It also contains a matrix that lists who they serve, and what specific services they provide, as well as population expertise and geographic limitations. We're going to bring in these organizations to provide assistance in proposal writing for 704. In the past, we've done pre-application workgroups, but, because of the timing and urgency of getting out the dollars, we don't have to time that. However, we're going to provide lists in the application kit, so you can access these individuals for technical assistance and grant help.

Q Is there a way that those of us who are connected to community-based organizations can have a follow-up roundtable discussion to figure out how we can help one another? Many organizations are not willing to work with other



organizations, because they might have something that others don't have. I don't care what community I work with, I'll work with anybody. I'm a nurse by profession and a member of ANAC (Association of Nurses in AIDS Care), which would be a very great resource for many of the people here.

Q We've talked a lot about the funding and epidemiology, and I wanted to mention that funding isn't following the research. We have a lot of good research that shows that preventive case management is what we need, yet many agencies are doing one-shot prevention. Why aren't we moving? Why is that happening? The other thing I want to address: My agency was funded to do some capacity building, and I'm starting to get a little frustrated about capacity building. We have a program to do a small-scale behavioral survey and we found that our population gets a lot of HIV education, but it's not affecting their behavior. So now I'm trying to get my funding going. I go to the CDC website all the time. I'm an experienced grantwriter and I can't crack these grants, because I don't have a researcher on staff. How can I compete with hospitals and teaching facilities that do? I want to recommend that CBOs are a valid place for prevention, research, and service. And I want the CDC to acknowledge that fact and fund us, because we have access to the people who need the services. I get annoyed because I keep getting flyers from teaching facilities, saying send us your clients for our research projects. I say, send me some dollars so I can give my clients some services.

Q Although we're talking about women, we seem to have forgotten that women have children. We need onsite daycare so that women can bring their children to their appointment. Maybe that's one of the obstacles that we set up so that they don't come in for care. I think it's really important that clinics or CBOs have daycare on site and appointments in the afternoon, after-school.

The other thing is quality assurance. I think you [in the federal government] need to get out of your office and into the field and talk to the people who are doing the frontline work.



Q Seventy percent of my caseload is women, and I find it difficult to provide women with information about the side effects of medication and the antiretrovirals, because there is not enough research about women. The other thing is, we need more women in clinical trials, and there are not enough clinical trials that include women of color. I have two recommendations: more dollars for research on women, specifically on antiretrovirals, and second, include women of color in clinical trials.

Q My frustration is outreach for adolescents. Adolescents are never here. There's no conference for adolescents. CDC is planning a conference in March or April for the performing arts. But when I go to these meetings to plan this, there are no adolescents there, but we're talking about adolescents. It's frustrating, because they are our next generation.

Q We have to look at what's going on in our cities and at the state and federal level, and ask, how long are we going to be slow learners? It took the CDC ten years to understand with this epidemic that there was a difference between a penis and a vagina. It took them ten years to find that difference. We're talking to the CDC as if they have all the answers, and that we need to comply with what they're asking. It's time for us to turn it around and say, "Now, wait a minute. You've had proposals for the last 15 years, how many ways do you have to tell us to tell you back what the needs are of these communities?" Give a boilerplate. Say, "We know at the CDC that this is what African Americans need, this is what we know about populations—what are you going to do about it?"

Why do we continue to say, "We don't have the money to pay for a consultant to do the proposals." Who is making the money on this epidemic? The communities are paying and as somebody said, "they don't even know about our communities, so we have to pay them." That's called parachute consulting. You drop in today, take your money, and bow out. We have to say to the CDC, "We're not going to do it anymore." We understand that good proposals are necessary, but don't judge us on stuff that you know already. Why

test us to see if we can give you back what we know that we've been telling you, so that you can take the statistics and tell us whether the proposal is written right or not?

If the needs assessment part is already done by you [at the CDC], you know what's going on. The only trouble is that you haven't sent somebody up here before 1999 to know that there are five boroughs. Now you know: There are five boroughs. But remember, there are parts of Manhattan that are not taken care of by GMHC, so don't just make Manhattan drop off the face of the earth. You look at upper Manhattan, and you see that some of the major organizations taking care of people of color are dying because they don't have the infrastructure money. So it's not a matter of how you write a proposal. Those organizations need a very good bookkeeper. Now, New York City has some of the best bookkeepers in the country. Some of the largest accounting firms in the world. Why don't you pay for a good accountant—not to come out of the CBOs' budgets—but to come out of the CDC budget, and help these organizations do their books the way you want to see them done. So that means a \$70,000 or \$80,000 salary, not what you give the organizations, \$25,000 to do something with, and then they hang themselves, because they can't get good people who know what they're doing for that amount of money. Give us training, yes. But that's not enough. We need someone on site to come in and help the staff persons do what they need to do, and it's not overnight training.

We need serious help so that they don't fail. And it's not cocktail language that our community needs. It's the language of day-to-day training onsite. In the community. It's got to turn around. I have heard for the last 15 years, "We don't have the money to pay a good proposal writer," "We don't have the money for infrastructure," and yet in the front page of the New York Times, yesterday, there was an article about how GMHC has lost some of their infrastructure money and so they had to cut their budget from \$26 million to \$22 million. Now, my sympathies are there for the people who lost the jobs in that \$4 million job loss. However, that \$4 million could have taken care of a lot of organizations here in Brooklyn, Queens, Staten Island, the Bronx and elsewhere. And yet, in a lot of cases, they say that they're taking care of us.

You've got to let us tell you, rather than your asking for proposals to be written in a way that you need, so that you see information that you already know.

Q I work for the Lower East Side Family Union as a community follow-up worker. Next month, I'll be doing case management and research. I don't know if it's just me, but I have problems with agencies and COBRA. I'm tired of being told what I can and can't do, because it's billable or not billable. If I have a client who is going through changes, don't tell me that I can't do it because it's billable, so the case manager has to do it—especially if the case manager is nowhere to be found, or doesn't want to deal with that issue.

COBRA is a good idea when it comes down to prevention. But it gets in the way of someone actually doing a job that needs to be done. And it also gets in the way of other agencies, when I can't refer my clients to an agency that has what I don't have, because they're COBRA. It can't work out because they're COBRA, we're COBRA, and the one in the middle is the client.

Q People always talk about how women are lowest on the totem pole. Well, adolescents are even lower than that. My recommendation is to address adolescents, and to address them in a much broader way than that of giving them condoms. One-shot deals are not going to do the trick. Prevention has to be seen in the context of sexual abuse, domestic violence, drug use, financial problems, crime. You can't bend HIV infection if you don't look at all the things that are going on in a woman's life, in a young person's life, that are impacting on their decisions. I've worked in an adolescent clinic—10 percent of those girls report a history of sexual abuse. If you've been sexually abused you will not take care of yourself. In fact, you will probably recreate that trauma. I believe that the most important thing we should be teaching young people is to take care of their bodies and their minds. There should be money for clinics that focus on all of these issues, but let's get children to care. Let's get people to care. Let's get them thinking about their bodies, thinking about their health. To talk about HIV and fund one little piece of that is missing the boat. It has to be put in the context of general health care. Fund clinics that treat people holistically.



- Q How do we access funding to add on to something that we're already doing, so that we can access people and reach them? There's a great need. The CDC needs to find a way to bring these funds out that does not lock out those who have access to the risk population in underserved cities—a way that encourages us to integrate AIDS/HIV education prevention in communities that are in denial about AIDS and women because they do not know and understand.
- Q For women who are HIV negative, status unknown, who do not have access to mental health services, are high risk: If you don't know your body, how are you going to take care of it? If you've been sexually abused and you don't love your body, why would you protect yourself? If you're in a domestic violence situation, why would you want to live? It's almost like giving somebody a syringe—it's the same thing. I understand why some people feel this is all about the government wanting to kill the minorities off. Some of the services are being cut, like mental health. It is a biggie.
- Q I appreciate your putting up there the recommendation I was trying to address in terms of more sensitive, women-centered literature. But could you be very specific, because the term "women-centered" is going to get us more of the same. I want literature that says, "Women are at risk because they have sex with other women." Period. Done. If you could even stretch yourselves to include the terms "lesbian women," "bisexual women," "transgender women." Today, at this hour, I am HIV negative. But I'm going to tell you that it scares me to death, because I can't go anywhere to pick up literature that speaks to me about how I can be safe. Women's sexual practices need to be in the forefront, in literature on paper, because there are only two small documents that were ever created. One had a court order against it, before it even got to us. And that was the one with a female on the front, it happened to be an African American woman with a glove on, and she's holding her vagina, and she's bare-breasted and she has the other hand, gloved, over her breast. It caused heart attacks—but that piece of information was very specific about women's sexual practices. We need more of



that.

- Q     Somebody mentioned women in prisons, and being incarcerated. We really need to see that up there as a recommendation, because that's a population that also suffers.
- Q     I feel that there have to be regional offices of advocacy for community based organizations, so that there is someone who can investigate this stuff on behalf of the community, when there are gaps in service. I'll give two examples. One example is a program that services sex workers in New York City, headed by Dr. Wallace. A service she needs is to have a residence to take women off the street who are HIV negative, so that she can save their lives and stabilize them. She can't find a place anywhere in New York City. That's a service that needs to be advocated by someone who has power and gives out money. The second is an agency in New Jersey that services women in prison, but because of the way the contract reads, they serve African American women. They will not share with another agency that serves Latino women. So we need an office of advocacy for community-based organizations to rectify some of these situations where there is grant money already in place.
- Q     We've been looking at societal problems and talking about how women are not served. My recommendation is that we stop making HIV the lens through which we look at the problems of women and that we ask the CDC to deal with women. Deal with women. And then we can include all those recommendations through this one recommendation.
- Q     I want to address adolescents again in reference to HIV education. As far as they are concerned, they are all expert in the matter. We have to find another way to give them this message without actually giving them the message. We find that when they have something else attached to the message, they are more receptive to listening to it. So that's my recommendation. That we be creative on how the message is given out, instead of just giving a condom and literature that nobody

reads and they just throw it away. I've been finding out that nothing is being done region-wide. So why don't we do something in the region?

Q I'm a member of ANAC (Association of Nurses in AIDS Care). We don't only welcome nurses, we welcome people who are healthcare professionals who are doing various services for the HIV population that is affected and infected. Next month, our meeting is on substance abuse, sponsored by Glaxo Wellcome. You can come and not pay anything, and you're welcome. The meeting takes place at Cicatelli.

Q [Getting back to adolescents] We need contests for getting kids in, using various things that we know are meaningful to kids. If we think they'll listen to us just because we're giving them a message, forget it. We need partnerships with sneaker manufacturers, or the people who make certain records, or the things that kids all buy. The communities, in other words, can't sponsor things within their budgets that make it realistic for teenagers to pay attention to the message. It's got to be more, and I'm glad to see people younger than me shaking their heads yes.

I would also like to see CDC have a community college run by people in the community who could then get the courses that they want. For example, a good consultant on bookkeeping could come in so that people could come in to be community-certified bookkeepers.

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## Recommendations

Workgroup B did not prioritize its recommendations. They were listed as follows:

- More women-centered brochures/informational pieces are needed for women who are at risk because they have sex with women. The literature needs to encompass the full range of women's sexual practices.
- Have a follow-up roundtable among provider agencies to share information and build collaborations.
- Community-based organizations (CBOs) are valid sites for research-driven services to be funded.

- Develop a mechanism to incorporate new research into existing contracts on a timely basis.
- Follow-up implementation of female condom study with funding.
- There should be on-site day care at facilities that serve women.
- Federal funding agencies should talk to people who are doing the work—i.e., more field observation should be done.
- More research studies should include women, and more research directed at women should be conducted.
- Provide more funding for antiretroviral studies for women.
- Include more women of color in clinical trials.
- HIV prevention programs need to address generation-to-generation needs. Develop a boilerplate: don't ask for information that is already known. Local agencies know where funding is needed.
- Hire consultants to provide fiscal-management technical assistance (TA) so that funding does not have to be expended from the service budgets of CBOs.
- Re-evaluate COBRA case management requirements.
- Female adolescent issues need to be addressed holistically—domestic violence, sexual abuse, drug issues (how these issues influence their decision-making skills.)
- The CDC should create opportunities for agencies that may not have HIV experience but that do have access to target communities.
- The CDC should enable the clinical hold rule.
- With managed care, women who are HIV negative and high-risk cannot access comprehensive mental health services to help keep them negative. Access should be provided to mental health services.
- The needs of women in prison need to be addressed and funded. These include family preservation and counseling for children and mothers who are heads of household and AIDS/HIV diagnosed.
- Fund advocacy services for CBOs.
- Stop making HIV the lens through which we view women's issues.
- There should be more regional meetings and other activities with periodic follow-up/feedback.
- The CDC should advocate on a legislative level for business to become more involved.
- Add a family focus to recommendations and evaluate how grants can encourage a family focus. Add to primary framework.
- We need to find new ways of communicating HIV prevention messages to adolescents/young people. Providers should be allowed flexibility to creatively address youth.
- Federal agencies need to enlist new partners (for example, the CDC could work with record and sneaker companies) to appeal more to teens.
- The CDC should provide funding to community colleges to provide management training for CBOs (e.g., bookkeeping, grant writing).

- HHS needs to fund programs that build self-esteem/job training.
- More research is needed on women's sexual practices and how treatment medications affect women and children. Information-gathering tools need to be updated.
- Funding is needed for programs to treat a person/woman/adolescent in a holistic manner.
- Funding is needed for mental health services and tutoring.
- We need to build a connected message. Don't isolate prevention from other issues.



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**Northeast & Caribbean Region**  
**HHS Community Meeting on HIV and AIDS:**  
**Confronting the Second Generation of the Epidemic**

## **Workgroups**

### **Workgroup C: HIV/AIDS and Substance Use Minorities and HIV/AIDS**

**Speakers:**

**Marsha Martin, D.S.W., Health and Human Services**

**Eric Goosby, M.D., National HIV/AIDS Policy Office**

**Claude Colimon, Public Health Service, Office of Minority Health, Region II**

**Facilitator:**

**Kathy Rohweder, The HIV Center for Women and Children**

**SUNY Downstate Medical Center**

In brief: Two scheduled speakers from the Substance Abuse and Mental Health Services Administration (SAMHSA)—Lucy Perez and Marty Bond—were unable to attend because of inclement weather. Marsha Martin, Special Assistant to the Secretary of Health and Human Services, and Dr. Eric Goosby, Director of the Office of HIV/AIDS Policy, substituted. Dr. Martin discussed the substance abuse block grants, which have an AIDS set-aside, and explained how SAMHSA, the Human Resources and Services Administration (HRSA), and the Centers for Disease Control and Prevention (CDC) were working together, across regulatory boundaries, to collaborate on funding. She also reviewed governmental barriers to needle exchange programs, while Dr. Goosby emphasized the importance of bringing injecting drug users into medical care systems. Ms. Colimon briefed participants on the activities of Region II's Office of Minority Health.

Issues raised by participants included lack of services for substance users, lack of involvement of substance users in administrative boards and planning groups, stigma and discrimination, and insensitive healthcare providers. Also raised was the issue of accountability for agencies receiving grants, incorporating flexibility into grants so that unused funds could be spent on related services, the need to increase mental health services for substance users, and support for alternative medicine.

The presentations of the speakers, and the ensuing discussions are presented more fully below. (Note: these are edited, both because of space limitations and because some of the discussion was inaudible on the tape. Some of the discussion section is drawn from notes taken while the workgroup was in session. In the discussion section, "Q" indicates comments from workgroup participants; "A" indicates feedback from speakers.)

**Speaker: Marsha Martin, D.S.W, Special Assistant to the Secretary, U.S.**

**Department of Health and Human Services.**

Dr. Martin described her role within HHS. Part of her work involves intervening on the Secretary's behalf with agencies such as SAMHSA, CDC, and HRSA. She discussed several federally-sponsored substance-abuse prevention initiatives that relate to HIV and AIDS care, including block grants.

The substance abuse block grant program, for example, has an HIV/AIDS set-aside, meaning that those dollars can be used to provide outreach and education to individuals who are in recovery and rehabilitation programs. Because block-grant funding is provided to states, the federal government has limited capacity to direct how it is used. This is why, Dr. Martin said, SAMHSA funding directed toward the epidemic may seem invisible: the majority of this money gets distributed with state and local tax-levy dollars. The same is true for mental health block grants. A small amount of money is available for education and knowledge development; it funds conferences, workshops, and demonstration projects. The public is entitled to know how block grants are used and to have its voice heard.

SAMHSA, HRSA, and the CDC have been meeting to collaborate on projects that will cross regulatory boundaries and link the issues of HIV and substance use. These agencies hope to develop an integrated-care model for substance users who are at high risk or who have HIV, although doing so is complicated. They report to different oversight authorities and have different funding mechanisms, and their funds get directed to different types of recipients—some monies go to the states, some directly to grantees, others to specific models of practice and care. However, these agencies believe it is essential to work together, because their messages share a similar purpose and audience.

Dr. Martin described a faculty development symposium recently held by SAMSHA's Center for Substance Abuse Prevention. It brought together a broad spectrum of health-care providers—social workers, mental health professionals, and public health officials, as well as academics and scientists—to discuss tobacco and alcohol prevention strategies in the adolescent population and how to apply these strategies to HIV prevention. "Before that two-day session was over," Dr. Martin said, "everybody in that room was well-versed on HIV and AIDS. They came to talk about tobacco and alcohol. When they left, they were talking about HIV in the context of addictive

research. So there are possibilities for shifts and changes in perspectives.”

On another front, the Secretary’s Office is also holding discussions with the Office of National Drug Control Policy on the issue of harm reduction and injection equipment. The goal is to promote an understanding of the importance of drug treatment and to get officials in the National Drug Control Policy office to view substance use as a health problem and not solely as a law enforcement issue.

As for needle exchange, Dr. Martin said that the Department of Health and Human Services is working to ensure that there is no absolute ban passed against the use of federal dollars connected to harm reduction. It requires delicate negotiations, because there are members of Congress who believe that needle exchange promotes behaviors that they personally find unacceptable. “We’re in an environment in which we have to be very careful when we talk about behaviors and the techniques we support and don’t support,” she said. “We’re trying to make sure that what we do promotes positive health and public health strategies for prevention.”

**Speaker: Eric Goosby, M.D., Director of the Office of HIV/AIDS Policy,  
Department of Health and Human Services**

Dr. Goosby, who along with Dr. Martin had been a panelist in the morning session, gave a short presentation. He explained that the Office of HIV/AIDS Policy is attempting to increase linkages between medical and traditional drug treatment program sites. “We have been unsuccessful in bringing drug users—and injection drug users in particular—into sustainable relationships with medical delivery systems,” he said. Dr. Goosby asked participants for ideas on how his office could support or enhance accomplishing this goal. He also asked for examples of discrimination directed against substance users and instances (without naming institutions) in which drug users have been excluded from or refused care. “I would like to understand the breadth and depth of that, so that I can benefit from your experiences,” he said, adding that he welcomed ideas on how one might target this problem and rectify it. He also asked for ideas on how to better partner medical professionals with drug treatment and mental health professionals.



**Speaker: Claude Colimon, HHS Region II, Office of Minority Health**

Ms. Colimon explained that the Office of Minority Health is relatively new, having been created in 1985. Its mission is to improve the health of minority populations, to better serve people of color, and improve health outcomes. Its activities include helping communities build coalitions, bringing people together to work in partnership, and strengthening community bases. Some of the new monies from the Congressional Black Caucus Initiative have been targeted specifically for this office.

Each HHS regional office has a Public Health Service Office of Minority Health (OMH). "I act as a go-between," said Ms. Colimon. "If you're in a program and you need support, I can try to find out who can assist you." The OMH Resource Center will assist in finding someone to provide technical assistance to CBOs that need grantwriting assistance, for example. The Washington number for the Office of Minority Health Resource Center is 1-800-444-6472; Ms. Colimon's number in Region II is 212-264-2127.

**Discussion of Issues: participant questions and comments ("Q") and speaker responses ("A").**

Q     You've correctly described the way it is. It's taken years for the government to figure out there was an injecting use population. They should have seen this before now. Why does it take so long to change that map? Why have the feds not really supported substance abuse treatment?

A     [Martin] This is why we are having this meeting and having it in Brooklyn. We need you to communicate to us. You are not in Washington, D.C., so Washington has come to you. There's always room to learn, grow, and change. With your input, we can make changes.

Q     We've continued to see this resistance from [the Mayor's] office. We're hurting in zip code 11212 [Brownsville in Brooklyn, New York]. We're hit very hard. But we are constantly presenting data to the Mayor's office and he's constantly resisting. We should have involvement in substance abuse planning.



- A [Martin] The Congressional Black Caucus earmarked money specifically for substance abuse treatment and services. They were very clear that there needs to be real money devoted to clinical intervention and rehabilitation. You can't just do prevention. They responded to those concerns by giving SAMHSA new money to be used in a different way to get services to people.
- Q You said that some money is allocated to states. Does the state present a proposal to SAMHSA to get that federal block grant?
- A [Martin] No. There's a planning process. Here's a challenge for all of you. The state mental health block grant has a planning process that encourages consumers of mental health services to be a part of it. The plan is sent out for review by the community. You are invited to attend public meetings to review the plans and make comments. Organizations have long advocated that the state substance abuse departments do the same thing and include those who are in recovery as part of that process. However, the Association of States Substance Abuse Directors has been resistant. In Geneva—you'll hear talk about the Geneva conference—there was a discussion that focused on the issue of allowing people in recovery to learn about the clinical process and to become part of the planning and funding distribution process. For the first time ever, this year SAMHSA held a five-day meeting of individuals and organizations involved in recovery and self-help. The intent was to start the process in a structured way, to teach those who have gone through treatment programs to come back and be part of the program policy structure.
- Q In terms of involving people in recovery and those who are active drug users: How are they recruited and who gets the information about when these meetings are set up? I have my ear to the ground and this is the first time I'm hearing about this. We need to know this information. I think you need to expand your announcement and recruitment process.

Q The terms “substance abuse” and “drug abuser” have been used as a label to isolate a section of the community. Drug abusers are very sensitive people, and they are aware when people are pulling the wool over their eyes. The second point I want to talk about is discrimination in care. In my own particular case, I admit to being a recovering alcoholic. Because I admitted it, I was denied certain medications, because they said that those were addictive medications. But the other medications they gave me were more harmful to my body and didn’t do the job. One of my AIDS infections was a herpes infection that went into my colon and I needed surgery to remove a tumor. When I told them the type of medicines I was on, they did not give me anesthesia, so I woke up in the operating room in serious pain and they thought it was a joke. They knew ahead of time what medicines I was on, but because of drug controls, they were afraid.

Doctors are afraid to give patients Percoset or drugs like that. There is a problem in the way that society looks at individuals. I don’t think that there’s a person on the face of this earth that is not addicted to some kind of chemical one way or another. So to say that somebody is a drug addict is just a way of putting them aside and finding a way to say that they are expendable. That is the crux of the matter. We too often exclude what the drug addict or person who is recovering from drug or substance use has to say because they are a drug addict. And we’re missing the point that they have a heck of a lot to contribute to society, and they’re no different than you or I.

My recommendation is to educate medical providers about pain management and sensitivity, not to stereotype someone, and say, “Oh, they’re just a junkie, so if they don’t show up on the second or the third of the month, it’s O.K.” Give them a call, find out what’s going on. Make them feel that they’re an important part of the community, that when they are not there, they are missed.

Q On the question of discrimination: I’ve worked for the federal government for over 23 years. I have witnessed discrimination in drug abuse. When it comes to substance abuse, the federal government feels that it is exempt from the ADA [Americans with Disability Act]. Agencies say they are exempt. So the federal government is doing a lot of talking, but it’s not producing. Since the feds are

the ones trying to get the cities and states to follow certain laws, they too should be held accountable for the violations of people's rights, and they should set an example.

A [Martin] The truth is, the federal government is exempt in a lot of environments and situations. It takes an active president, like President Clinton, to change that.

Q Medical school students should have to serve in the community to get a feeling for what is going on. Have peer education in medical school. State governments need to get more involved with substance abuse clinics—for example, methadone clinics—to give more support to these clinics.

Q I come in contact with people in different communities. When they come to the hospital for drug treatment and other medical problems, there is not enough research out there so that they can get proper care for their needs. Patients do not present themselves for help unless they are in severe pain. People keep themselves out of care because they are afraid or feel alone. We need literature that tells patients where they can get help.

Q There needs to be a change in clinic standards. Patients need to say how treatment has affected them and their families.

Q Physicians do not know how to react to drug addicted patients. Medical doctors need to be more aware of their problems—for example, if someone comes in with a collapsed vein.

Q If you're going to put out information, put it into different languages.

A [Martin] The government cannot control this. It is a local planning process. Citizens need to be more active in the state, and advocate for their needs.

Q We live in a society in which there are many undocumented minorities—living,



working, going to church, loving. When they get sick, they do not go to physicians because they are afraid to go to them. They use herbal remedies. What can we do? This helps spread disease.

A [Martin] The federal government has said that federal money can not be used to treat undocumented individuals.

Q How can we give medications to individuals with both substance abuse and HIV, when we don't make medications available to ensure success in substance abuse treatment?

A [Martin] Substance abuse hasn't been a major focus. We need to build a new approach that focuses on substance abuse and HIV. The challenge is, how do we take our limited substance abuse information and link it to HIV? We need to define standards of treatment.

Q Money needs to go directly to the city. We need to break the controls of the lobbyists and those elected to Congress.

One of the obstacles is the attitude of providers. I'm not necessarily talking about doctors, but also providers in agencies like Public Assistance. I have had clients who have come to me crying. I've spoken to some individuals who are so nasty that I myself want to say, "Why are you working at this agency? You don't even like these people." I think this is very important. The drug user has a split between two thoughts. One of them is, "I want to do the right thing." And the other one is, "Gee, I have a desire for a shot of heroin." A relationship with providers can help them go from one place to the other. But too many times a drug user going through treatment has to go through people with bad attitudes, accusations, and discrimination. When I say discrimination, I don't mean classically white, black, or Hispanic. These are same-race, same-nationality medical providers who are so nasty that middle class, normal people would be horrified to be serviced by any of them. I would be horrified to be treated the way many of my clients are treated by these agencies. Let's talk about what to do with what we have. If you are really serious and consider this a crisis, I would

say, immediately work on the attitude of the providers. Make war on it. Educate. This city needs education for providers on how to treat people, how to understand a drug addict. Pass patients' rights to protect them against these attitudes.

Q I was at the last SAMHSA meeting in Washington, D.C., and only one or two people from New York showed. Definitely, no one from Brooklyn was there. They did not pay for your hotels or transportation, but just to be there and let them hear your voice should have been enough to get you there. A lot of the issues that were brought up are the same issues brought up here: you need to deal with stigma, you need to educate health professionals. But also [you need to educate] the judges and lawyers. Because if someone who is HIV-positive comes before a judge or a lawyer who doesn't know that this individual needs their medications when they send them to jail, if they miss a certain number of dosages this can replicate the virus more.

Also, the block grants that we spoke about earlier: The federal government gives these grants to the state, the state gives them to different agencies who apply for them, but they need to come up with stricter rules as far as how long it should take for that agency to accomplish those goals. If you apply for a block grant and you do exactly what you said you were going to do and you meet your goals and you have left-over money, you should be able to use that left-over money for something else that your agency might do. Why can't that additional money be used within your agency?

A [Martin] It's tricky. You don't want to create incentives for agencies not to spend the money. I appreciate the sentiment, however, because it's very important.

Q As a provider, I don't like the way that people say, "Substance abusers, they go into these fits, they get methadone, and they come out and they go home." We need certified psychologists and psychiatrists to sit down one-on-one with a

substance abuser and allow that person just to vent, because the ground rule is, you have to find out why this person is using drugs. Find out the reason why someone really started using drugs. A lot of substance abusers are not able to talk about their issues.

Q A lot of rehab centers have problems with medications that people with HIV are on, especially when it comes to pain management. You mentioned this new money that was coming in, asking for people who are in drug treatment to have some input into policy. I want to applaud you tremendously on that one, because that's what we've been looking for. Many of us have felt like we did not have a voice.

A [Goosby] Let me ask a question about organizing people in recovery. There are drug-user unions in Europe that have been very effective in helping some of the European countries improve their drug treatment programs. How well attended would an HIV-recovery community meeting be?

Q We meet twice a year at an AIDS retreat, and we have a very large turnout. I think it would be well attended.

A [Goosby] If the federal government held meetings that asked people to self-identify, would people come and feel comfortable? You don't often hear of people going in front of members of Congress as drug users or former drug users affirming the importance of substance abuse treatment dollars to the Substance Abuse and Mental Health Services Administration and asking for support for public health models for recovery. Part of SAMHSA's efforts are to help people who have gone through recovery programs to appreciate the funding process, the legal process, the Congressional process, and understand how the resources are disseminated. That's asking people to go way beyond where the substance abuse rehabilitation community traditionally has gone. It's about forming a constituency, and helping people to have a voice.

Q Getting back to the health issues and Medicaid: all these HMOs (health maintenance organizations) tell us what type of medication or treatment we



should get. I feel that doctors who practice holistic and alternative medicine are discriminated against and not being given the opportunity. Nor have I seen studies about alternative treatments for HIV or substance abuse. I believe the CDC and FDA have a vested interest in pharmaceutical treatments. I believe it's a conspiracy in the way that you're omitting the doctors who practice holistic medicine.

A [Martin] Actually, the NIH has started to fund alternative medicine research efforts. So again, it's taking some time, but it's in the mix.

Q There have been a lot of good comments made. We need to remember that the same way active substance abusers are judged, so are recovering addicts. And they talk back and forth to each other. In this profession, one of the things that we have to remember is to keep in mind what our biases are when working with these individuals. I've seen how good professionals in the field have biases toward people in recovery, active substance users, people living with HIV and AIDS. And I'm appalled by it. A comment was made about case management and working with somebody who is HIV positive who has to take meds and is still using substances. All you can do with that is harm reduction, harm reduction, harm reduction. It's ongoing education. Just because we have our degrees and certifications, doesn't mean that we can't continue to learn from each other. There has to be that exchange of information.

A [Martin] One of the reasons why we have the Office of Minority Health is because there are resources available to minority health organizations to help address health disparities and to form coalitions to reach out to communities of color. The Office of Minority Health began as a way for the federal government to make grants available directly to communities. Not through the states, not through the county, not through the city, but through organizations that promote healthy behaviors and work to mitigate against the biases in practice that result in disparities.

## **Recommendations:**

Workgroup C identified its three priorities as: 1) improved education on substance abuse issues for medical providers and community providers; 2) involve substance users in decision-making bodies; and 3) fund supportive services.

### **Improve education of medical and community providers:**

- Educate medical providers to be sensitive to the needs of their clients and symptoms.
- Community service should be part of medical school.
- There should be ongoing education for providers.
- Train providers in pain management/symptoms/harm reduction.
- Improve standards of care for treatment centers.
- Expand AETC (AIDS Education and Training Centers) curriculums to include substance abuse issues.

### **Involve substance users in decision-making bodies:**

- Include substance users and minorities in planning groups.
- Have substance abuse agencies "sit at the HIV/AIDS table" to better integrate care.
- Involve substance users in planning committees and oversight boards.
- Support organizing users to serve as their own advocates.
- Provide educational materials for targeted groups "in their own language."

### **Fund supportive services:**

- There should be more research on outcomes of harm reduction. Include a flexible definition of success.
- Promote needle exchange demonstration projects.
- Integrate mental health services.
- Fund alternative medicine services.
- Fund services for undocumented immigrants.
- Demand accountability from agencies receiving grants.
- Funnel money through cities, not states.
- Increase resources for community education, especially to substance users about HIV services. Providers need to advertise their willingness to serve this population.

### **Additional recommendations submitted by Workgroup C include:**

- Increase awareness of and avoid stigma created by "labeling" populations.
- The federal government should also be accountable to regulations (i.e., not exempt from AIDS anti-discrimination laws).
- Outcomes of harm reduction should be measured (develop different definitions for "success").
- Provide respectful, accessible services for active users.
- Address standards of care for providers of substance abuse/HIV services.
- Expand AETC curricula to include substance use issues.
- Improve support systems for active substance users to increase ability to take meds.

- Pass a patients'/users' "Bill of Rights."
- Educate medical providers so that users receive respectful, competent treatment.
- Allow flexibility, so that additional monies can be used on related services.
- Increase mental health services for substance users. Evaluate their needs.





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**Northeast & Caribbean  
HHS Community Meeting on HIV and AIDS:  
Confronting the Second Generation of the Epidemic**

## **Workgroups**

### **Workgroup D: HIV/AIDS Clinical Trials AIDS Treatment**

#### **Speakers:**

**Deborah G. Katz, M.S.R.N., National Institutes of Health, NIAID, Division of AIDS**  
**Richard Klein, Food and Drug Administration, Northeast Region**

#### **Facilitator:**

**Dilcia Granville, M.S.W., Food and Drug Administration, New York District Office**

In brief: Workgroup D focused on clinical trials and the regulatory processes of the Food and Drug Administration (FDA) that impact on HIV/AIDS-related medications and devices. Deborah Katz represented the National Institutes of Health's Institute of Allergies and Infectious Diseases (NIAID), Division of AIDS. The FDA was represented by Richard Klein, from its Office of Special Health Issues in Rockville, Maryland, and Dilcia Granville, who conducts community outreach for the FDA's local office in Brooklyn. Mr. Klein explained that HIV-related responsibilities of the FDA include approving the release of therapeutic drugs and vaccines, HIV diagnostic test kits, and barrier devices such as condoms and gloves. Ms. Granville described the FDA's MedWatch Program, which tracks and provides information on product side effects and adverse reactions. Ms. Katz reviewed the organizational structure of NIAID and programs it funds in Region II, including university-based academic research studies and CPCRA (Community Programs for Clinical Research on AIDS), which is designed to bring research closer to the community.

Issues cited during the discussion included lack of oversight for dietary supplements, the need to publish easily accessible follow-up data on research, the complexity of current drug treatment regimens and whether or not the pressure to approve new drugs quickly is helpful or harmful, lack of appropriate awareness messages, and the need to include women and children in clinical trials.

The presentations of the speakers, and the ensuing discussions are presented more fully below. (Note: these are edited, both because of space limitations and because some of the discussion was inaudible on the tape. In the discussion section "Q" indicates comments from workgroup participants; "A" indicates feedback from speakers.)

**Speaker: Dilcia Granville, Food and Drug Administration, New York District Office**

Ms. Granville, who served as a moderator, opened the Work Group session by introducing the speakers and asking participants to introduce themselves. Later in the discussion, she discussed MedWatch, the Food and Drug Administration (FDA) reporting mechanism. Anyone who has a side effect or adverse reaction to any of the products regulated by the FDA can report it to MedWatch at 1-800-FDA-1088, or check its website, [www.fda.gov](http://www.fda.gov). As community outreach director for the FDA, Ms. Granville advertises this service on television and radio appearances. When she makes site visits to community-based organizations, she posts the numbers. "Nurses call me all the time," said Ms. Granville. "If you log on to [www.fda.gov](http://www.fda.gov) you'll find MedWatch and you will see all the reporting. If you don't have a computer you can always call in or fax a request and I can tell you from my computer if that product has any incidents. MedWatch is for anyone, minor or adult, who experiences any kind of adverse reaction to a drug."

**Speaker: Richard Klein, Office of Special Health Issues, Food and Drug Administration**

The mission of the Food and Drug Administration (FDA) is to serve as a regulatory agency, rather than to perform or fund research. It does, however, review research and provides oversight for quality assurance. The FDA regulates drugs, biologics, drugs, vaccines, food and cosmetics, veterinarian drugs, devices, and radiation emitting devices. The goal of that regulation, said Mr. Klein, "is to ensure that the products we regulate are safe, effective, properly manufactured, designed properly, truthfully labeled, and have adequate directions for their use."

He also explained that the FDA operates within a strict legislative framework set by Congress. Although many think the FDA should be advising companies on what products to make, in what quantity and at what cost, the agency has no authority to control any of those variables.

The FDA has the authority to examine research that supports a drug or product. The FDA asks, "Were the studies well designed and adequately controlled? Was the data validated and verified? Were the statistical models correct and adequate?" The FDA also



investigates for quality control: "Is the company capable of making a consistent product? Has it been shown to be safe and effective in a particular population for a particular use? Has it been properly labeled and made available to people to use properly?" Also examined is the manufacturing process, to ensure that production plants are clean and sterile. The FDA also reviews advertising, which is based on labeling, and it has the ability to limit how drugs are advertised.

HIV-related responsibilities at the FDA have centered on therapeutic drugs and vaccines, which are both drug and biologic products. It regulates diagnostic test kits for HIV, to make sure that they are specific and sensitive. It also regulates medical devices. With regard to HIV and AIDS, these consist primarily of barrier devices such as condoms and gloves. The FDA is also responsible for the safety of the nation's blood supply, and in this capacity it sets the standards for testing, processing, handling, and delivering blood products.

Recently, the FDA established a regional Health Fraud Task Force, comprised of federal, state, and local government agencies and community-based organizations. The goal of the Task Force is to develop strategies to combat the dissemination of fraudulent medical treatments and devices to people with HIV/AIDS. For further information, contact the New York District Office at 718-340-7000, ext. 5528.

Mr. Klein explained that the Food and Drug Administration cannot release information on clinical trials for drugs under study because of confidentiality restrictions. "Since companies are required to give us information about the status of their trials, their manufacturing process, and drug components, we have a responsibility to ensure that none of that information is released to anyone else," he said. "This is information that would be valuable to a company's competitors and to people who want to invest in drug companies." Mr. Klein said that he advises people who want information on clinical trials to check publicly available data sources.

**Speaker: Deborah G. Katz, M.S.R.N., National Institutes of Health, NIAID, Division of AIDS**

Ms. Katz presented slides detailing the organizational structure of the National Institutes of Health, including the Institute of Allergies and Infectious Diseases and its Division of AIDS, and the Office of AIDS Research. The goal of NIAID's Division of AIDS, which was established in 1987, is to increase basic knowledge of the pathogenesis, natural



history, and transmission of the disease, and to promote treatment and prevention.

"We've come pretty far in gaining a better sense of the pathogenesis of this disease," said Ms. Katz. "We know more about this disease than we know about any other viral disease. We've made a lot of progress in treatment. We know a lot of things about nonvaccine prevention, and we're just beginning to increase our emphasis on vaccine prevention."

Programs funded by NIAID include research and treatment programs, women's programs, and adult and pediatric clinical trials. Examples of the Institute's HIV/AIDS projects include the AIDS Vaccine Group, HIVNET (HIV Network for Vaccine Trials); the Terry Beirns Program for Clinical Research on AIDS; and the WIHS (Woman's Interagency HIV Study) program in New York, as well as the Adult Clinical Trial Groups at Bellevue Hospital, Mount Sinai Medical Center, Memorial Sloan-Kettering Cancer Center, and Rochester which are primarily university-based academic research studies. Another example is CPCRA, which was designed to bring research closer to the community. Vaccine prevention research is being conducted at New York University and the New York Blood Center, and there is an AIDS Vaccine Evaluation Group at Mount Sinai.

Several of these programs, encompassing funding of over one hundred fifty million dollars a year, are up for re-competition, with awards to be made at the beginning of Fiscal Year 2000. Several pediatric grants will be re-competed the following year.

"We decided to re-compete all of the clinical money at the same time because we wanted to rethink where we're going in our clinical trial efforts," said Ms. Katz. Workgroup participants were asked to recommend directions for funding clinical trial groups in New York.

The NIH and NIAID receive funding from Congress, although they have direct reportage to the Executive Branch and the President. AIDS is well-funded, Ms. Katz said. Does AIDS have more money than other diseases? When asked that question, Ms. Katz says she responds by saying that more money should be available for research on *all* diseases, but that AIDS is unique in that none of the other life-threatening diseases are transmittable or predominately strike people during their most productive years of life. In addition, AIDS research is important because what has been learned is being applied to other diseases such as cancer.

Ms. Katz also focused on triple drug therapy and noted some of the questions that need to be answered during a drug trial: How are the drugs to be used? How do people take them? What nutritional support is necessary? How do we better understand how to use these drugs? How do we get better ones? What about individuals who can not take these drugs any more—what is available for them? How do you design trials to study how all of this works?

**Discussion of Issues: participant questions and comments (“Q”) and speaker responses (“A”).**

Q      What is the FDA doing about all these claims for dietary supplements?

A      [Klein] Several years ago Congress passed the Dietary Supplement Act, which essentially took all dietary supplements out of the FDA’s regulatory sphere. The FDA has no regulatory authority over supplements except as foods. If they are not adulterated and can be safely eaten, the FDA does not have any regulatory authority. If, however, a claim is made that a product can affect a disease, then the FDA can insist on clinical trials and appropriate labeling. In most cases, companies opt to remove disease indications from a label. For example, if a label said a product was useful for treating HIV or increasing CD4 count, the FDA would consider that indication of a disease and insist that the claim be removed. But if the label were to say, “taking this nutrient could boost your immune system,” the FDA would not have jurisdiction because it is not a specific disease mention. This applies to supplements produced both within the United States and abroad. “If you find a labeling or advertising promotion that you think crosses the line of disease category,” Mr. Klein advised, “then you can call the FDA and we’ll investigate whether it qualifies for action. If it is imported, we can release an import alert so that it can’t be imported; if the product is produced here, we would try to stop it from being sold until the label and promotion are changed.”

Q      What is the FDA’s position on approving a drug with potential for children?

There are two steps, and I'm very confused about it. I know it goes to NIH, then FDA. Can you clarify?

A [Klein] Back in 1987, there was a guidance document at the FDA that said women of childbearing potential should not be enrolled in a Phase I clinical trial and most IRBs (internal review boards) did not want to include women, because the potential impact on a fetus was not known. In 1993, the FDA published guidelines that went the other way, stating that women of childbearing potential should be included in clinical trials if they have a life-threatening illness. But it was not a regulation, it was a guidance document. About the same time, the NIH required that women be included in studies that were funded through their Institutes. Slowly, things are turning around. Last year, the FDA proposed a regulation that would give it true regulatory authority on the inclusion or exclusion of women. A Request for Comment was published in the Federal Register and hundreds of comments were returned. The FDA is now reviewing these and incorporating them into the final regulation. It's been a long process, because of the volume of comments and the need to categorize and address them. The regulation is expected to be out this year.

Q What about dosages?

A [Klein] The 1993 FDA guideline had two goals—the first, to enroll women in trials, and second, to determine if there are discernable differences in the response to dosages. The FDA also has guidelines that ask sponsors who are bringing a drug to the FDA for approval to identify the demographics of trial participants according to the seven racial and ethnic groups identified under Title VII. Pediatric trials have a different set of standards: the data presented does not have to be from a company's primary controlled study, as long as there is data available on its effectiveness in pediatric populations. This year, the FDA published a final rule that requires companies that manufacture drugs that might be useful to children to conduct studies to support the data on the labeling. So there is movement in the direction of improving pediatric drug labeling and studies—but



without a regulatory mechanism to force companies to do it, it's difficult to get compliance. The studies are expensive to do and the treatment population is small.

Q What's happening with vaccine trials?

A [Katz] You may not know that we have more than 3000 brave individuals who have participated in vaccine trials in this country, both in Phase I and some Phase II trials.

Vaxgen, which is the company that makes the product, has started the first Phase III clinical trial. We hope in the next couple of years to do many more Phase III vaccine trials.

Q If a person becomes resistant to one protease inhibitor, does he become resistant to all protease inhibitors? Is there anyway that he could fight back?

A [Klein] They are not mutually exclusive. Some drugs have cross resistance, which is part of the complication of how to use drugs once they are on the market. With one type of protease inhibitor, you may be limiting your ability to respond to other types of protease inhibitors later on in treatment. With another protease inhibitor, you may have a better resistance profile. It depends on what drugs are combined and how. That's what the treatment guidelines try to address, but no one has the answers or exactly how different combinations will work. It's important to do the studies and accomplish the regimens that work. And that's different for different people.

Q I was wondering if you could talk a little bit about medication regimens.

A [Klein] The goal is to make the regimens easier, with fewer pills. Research is aimed at refining drugs so that blood levels can be maintained longer and developing new drugs that are more easily regimented.

Q Are they coming up with anything new? We have a lot of clients that are dying. A friend of mine just died, and he could not take his medications at all because of all



the instructions. They have to come up with something.

A [Klein] There are new formulations for pediatric care. One problem the FDA has, and everyone has it, is determining when something is effective and how effective it is. And that needs to be balanced against the speed of getting a product on the market and being able to properly label. Look what happened recently with the diabetes drug [troglitazone, which can cause severe liver damage]. The tremendous challenge for the FDA is to determine when there is enough data to say a drug is safe and effective. There can be an incredible amount of pressure to have a drug hit the market.

Q People only hear that Magic Johnson is cured. "You don't have to worry, there's a cure." I don't think the FDA and the other federal agencies are providing the type of ongoing message support that shows continuity. There's no national agenda. It's a non-issue. In this last Congressional election, not one New York State candidate that I know of [raised the issue of AIDS awareness]. In a city where we had the first 100,000 cases of AIDS no mention has been made by the mayor announcing this as a priority.

A [Klein] I think this is a really big issue. All of the funding for disseminating messages comes from the pharmaceutical industry. We don't have any resources, and nobody believes us because we're the government.

Q Another problem is long-term follow-up with clinical trials. Once a trial is over, you lose the patient. You can't follow patients because they sign an informed consent to participate for a given number of weeks, and when the study is over you have to say, "Sorry, we can't see you anymore, go back to the provider again."

A [Klein] There are requirements for annual adverse drug-reaction reports from the companies that make and sell drugs so that there is some long-term use data.

Q We don't have access to that information. We lose patients.

A [Klein] Treating doctors report adverse drug reactions to the companies whose drugs they prescribe. The FDA set up the MedWatch program a couple of years ago so that people can call the FDA directly, instead of going through the drug manufacturer. There are a lot of trends that show up. That's where the reports of diabetes showed up with protease inhibitor use, and the product was re-labeled.

Q This is a recommendation: that the MedWatch number [1-800-FDA-1088] be in the same place you have the poison control number. It needs to be promoted.

Q When you are in a Phase I, II, or III trial and it is called only by a number-FTZ14387 or something like that-you don't necessarily know anything about the drug. There are no descriptive terms about the trial. There should be-patients would like that.

Q Is the NIH funding dietary research? Nutrition?

A [Katz] The Office of Alternative Medicine is just beginning a very large study on a full range of research and clinical trials.

A [Klein] From the FDA point of view, in order to make a product a regular, approved therapy, you have to have a label based on a clinical trial that shows the product is safe and effective. The problem with most alternative products is that they are not proprietary entities. No one holds a patent on them. To study new products you need to know what the active ingredient is, how much of it is in there, and you need to be able to show that you can create it consistently. So in other words, you have to be able to homogenize the product so that you can measure it and make sure it is always the same product. That's a real challenge for people who are trying to show benefits of alternative medicines. When you start in the laboratory, you know what the molecular structure is that you are dealing with. When you deal with these kinds of therapies, it's very hard to work these details out. So it becomes an expensive proposition, and if a company can't patent the product, that's another problem.

- Q I have a question about FDA-approval of diagnostic tests. There's been a lot of talk about changing the guidelines and regulations for women based on a recent Hopkins study. Guidelines aside, my question is, when these model blood tests were developed, did you require that gender differences be shown in diagnostic tests?
- A [Klein] I don't know if that was looked at. I imagine that there were mixed gender cohorts when the product was studied. In relation to the Hopkins study, I don't know what difference there would be, because it was measuring the amount of virus in the blood, and their conclusion was that that amount varies in different stages of disease in the genders. But it used the same instrument to look at how much virus is present in the blood. Are you asking if the test is less effective or sensitive in women?
- Q I'm asking if it's sensitive to hormonal differences.
- A The test is not less effective or accurate when testing women, because what it is measuring is the virus present in the blood. In short, hormonal levels would not affect the ability to measure the viral particles present in blood plasma.
- Q Scientists here at SUNY Downstate [the host facility for the conference] are very much interested in that issue. What does a viral load level mean for women? We're trying to figure that out. If there is a difference in viral load levels, does viral load "x" in women mean the same good or bad thing as it does in men? It's important to address.
- Q Another issue is that people don't travel to other boroughs to participate in trials. The issue is geographic. You need to look at where the numbers are. You don't have to have the absolute most famous facility as a clinical site. There is a need to disperse clinical research, and that has not been done. Community sites have been proven to be effective.

## **Recommendations:**

### **Workgroup D: HIV/AIDS Clinical Trials; HIV/AIDS and Medicaid**

The worksheets submitted by workgroup D reviewed only its three top recommendations, which can be summarized as 1) make clinical trials more available; 2) create a database to be used as a resource; and 3) increase awareness of adverse reactions.

#### **Make clinical trials more available:**

- Clinical trials should be available in neighborhoods.
- Increase dispersal of clinical research opportunities.
- Insure quality through partnerships between community-based organizations and academic centers.
- Access to trials: define the roles of high-tech and community trials and link them strategically.

#### **Create database to be used as a resource:**

- Maintain (fund) a long-term observational database on study participants. Insure access to the information—e.g., that its existence is publicized, published, and made available.

#### **Increase awareness of adverse reactions:**

- Include advice on the participant enrollment form regarding mechanisms for reporting adverse reactions after the trial is completed.
- Patients/subjects of clinical trials should be given the MEDWATCH contact number (1-800-FDA-1088).
- Raise the profile of information on how to report adverse reactions to the public in general and to consumers in particular





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**Northeast & Caribbean Region**  
**HHS Community Meeting on HIV and AIDS:**  
**Confronting the Second Generation of the Epidemic**

## **Workgroups**

### **Workgroup E: Discrimination Concerns** **Social Security Benefits**

#### **Speakers:**

**Michael R. Carter, Health and Human Services, Office for Civil Rights, Region II**  
**Fernando Morales, Health and Human Services, Office of General Counsel, Region II**  
**Angela McDonough, Social Security Administration, Social Insurance Disability Program, Region II**

#### **Facilitator:**

**Lonjette Garland, SUNY Downstate Medical Center, HIV Center for Women and Children**

In brief: Workgroup E reviewed the issue of civil rights for persons with AIDS and the enforcement powers of Health and Human Services' Office for Civil Rights (OCR). It also examined the Social Security Administration benefits available to those who are disabled by HIV or AIDS. Michael Carter and Fernando Morales represented the Office of Civil Rights; Angela McDonough, who works for the Social Insurance Disability Program, presented on behalf of the Social Security Administration. OCR is charged with ensuring that all federal civil rights statutes are complied with by agencies that receive funding from HHS. It investigates complaints, conducts compliance reviews, and offers complaint resolution. Ms. McDonough discussed the filing and processing of disability benefits available to those with HIV/AIDS. She noted that health care professionals can help their clients with AIDS by identifying potential claimants and, once an application is filed, collecting medical evidence to support the disability claim.

Issues raised in this workgroup include dual discrimination on the basis of both HIV/AIDS and race; lack of information on HIV/AIDS in languages other than English; and the need to increase awareness of civil rights among those who are infected and affected by HIV/AIDS. The Office of Civil Rights, (212) 264-3313, is available to help people pursue their rights.

The presentations of the speakers, and the ensuing discussions are presented more fully below. (Note: these are edited, both because of space limitations and because some of the discussion was inaudible on the tape. In the discussion section "Q" indicates comments from workgroup participants; "A" indicates feedback from speakers.)

**Speaker: Michael R. Carter, Department of Health and Human Services,  
Office for Civil Rights, Region II**

The Office of Civil Rights (OCR) of the Department of Health and Human Services was founded in 1968 as part of the former Department of Health, Education, and Welfare (HEW). Its charge, as mandated by Congress, is to ensure that all federal civil rights statutes are complied with by any agency or institution that receives HHS funding. This includes hospitals, nursing homes, daycare centers, foster care and adoption agencies, and departments of social services and welfare. Among the statutes enforced by OCR are Title VI of the Civil Rights Act of 1964, which addresses cases of discrimination due to race, color, and national origin; Section 504 of the Rehabilitation Act of 1973, which has jurisdiction over both mental and physical disabilities; the Americans with Disabilities Act of 1991; and Subpart G of the Hill Burton Act of 1946, which deals with emergency services.

Seventy to 75 percent of OCR's investigations are begun by complaints from individuals. OCR also conducts compliance reviews, which it can initiate based on anecdotal information, media stories, or an issue of compelling national interest. In recent years, OCR has moved towards complaint resolution. Under this approach, OCR provides technical assistance to offending agencies who may be in violation because of an absence of information, rather than outright discrimination.

"In most cases, it's a matter of enforcement, of changing the way that people think, the way they have traditionally done business," Mr. Carter noted.

Title VI is an important statute for persons with AIDS or HIV, Mr. Carter said, because they may suffer from dual discrimination. For example, they may be denied services based on both their disease and their race or national origin. Another issue is the absence of HIV/AIDS information in languages other than English. This can be a significant access problem, especially in New York, where 175 different languages are spoken. To address this problem, OCR released a LEP (Limited English Proficiency) memorandum advising health facilities of the need to provide multilingual material. OCR can also initiate limited scope reviews, which randomly check the policies of hospitals or nursing homes to ensure that a facility does not discriminate against HIV/AIDS patients. Over 200 such reviews have been performed over the last eight years.

Since 1984, HIV cases have been "fast-tracked" by OCR and given the highest priority. This means that AIDS/HIV complaints are immediately assigned and moved for



processing. All parties are notified within 48 hours. However, despite this, OCR has received surprisingly few AIDS/HIV-related complaints, perhaps 50 in all. In part, this is because complainants use the court system or file with City or State Commissions of Human Rights to redress grievances.

**Speaker: Fernando Morales, Regional Civil Rights Counsel, Department of Health and Human Services.**

Mr. Morales, the legal advisor for the Office of Civil Rights, works closely with Mr. Carter. Persons with HIV and AIDS suffer discrimination in all areas, Mr. Morales noted, adding that he has found in his work with the Office of General Counsel that many individuals are not aware of their legal rights and are willing to accept obvious discrimination as something “to just be expected.” Examples of discrimination include dismissal from employment because of the need to take time off for medical treatment or denial of admission to a nursing home because of HIV status.

The two statutes primarily enforced by OCR are ADA (Americans with Disabilities Act) and Section 504 of the Rehabilitation Act, which essentially provide the same protection against discrimination for people with disabilities. The agency does not enforce employment discrimination complaints, unless the entity that is being complained about receives federal funding through HHS. In cases that involve a non-HHS-funded employer, the best place to file a complaint is the EEOC (Equal Employment Opportunities Commission). Often, an agency’s funding source is not readily obvious. However, if an agency accepts Medicaid or Medicare, this is an indication that it receives federal funding. If the employer is federally funded, the OCR then has to ascertain that the conduct being complained of occurred not more than 180 days prior to the time the complaint is brought.

When OCR receives an ADA complaint from someone with HIV/AIDS, the first step that OCR must take is to determine if the person can be declared disabled under the law. “Now, understand,” cautioned Mr. Morales, “Disability doesn’t mean exactly what everyone thinks it means. It has a very technical definition. Under the ADA and Section 504 of the Rehabilitation Act, a person is considered disabled if he or she has a physical or mental impairment that substantially limits a major life activity (e.g., work or reproduction). Under ADA, a person who is HIV positive but asymptomatic can be

considered disabled. Mr. Morales recommended that everyone read the recent Supreme Court decision of *Brandon v Abbott*, which confirmed this right. Prior to this decision, many individuals suffered discrimination and were unable to get redress for discriminatory conduct.

Mr. Morales cautioned workgroup participants to be aware that disability has different meanings in different contexts. Under Social Security guidelines, for example, disability has a much different meaning than under ADA guidelines. The Social Security Disability (SD) program defines “disability” as the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months. “The definitions of disability under the statutes, as you can see, are very technical, but the distinctions are critical,” said Mr. Morales. “A person may have a physical impairment that limits a major life activity, thus being ‘disabled’ under the ADA, yet still have the ability to engage in substantial gainful activity, thus not meeting the definition for disability under the SD program.”

Under ADA, a potential claimant has to prove that he or she is what is known as a “qualified individual” with a disability. In the context of employment, this means that the “essential requirements of the job” can be met, with or without a reasonable accommodation. Examples of “reasonable accommodation” include taking time off from work to take certain medications or to visit a doctor.

If the defined hurdles are met, a person can bring a complaint to OCR by calling 212-264-3313.

### **Speaker: Angela McDonough, Social Security Administration, Social Insurance Disability Program**

The Social Security Office is a lifeline for people who are disabled because of HIV or AIDS infection. Those who work with people with HIV can help by identifying potential claimants and, once a person has filed an application, by collecting medical evidence. Social Security has two benefits programs: Title II, in which eligibility is based on work history, and Title XVI, Supplemental Security Income (SSI), in which eligibility is based on need.

Ms. McDonough interacts with field offices and state disability determination agencies to make sure policies are administered correctly and on a timely basis. Each state

has one state government agency that makes the disability decisions for Social Security. Social Security claims can be filed in person, over the phone, or with the assistance of a third party. When it processes a Title II claim, the first thing that the Social Security Office must do is determine that a claimant meets the insured status requirement—that is, that he or she has worked long enough to qualify. For SSI benefits, Social Security determines whether or not a person's income and resources fall within eligibility limits.

For SSI claims, when there is an allegation of HIV, the Social Security Office can start "presumptive eligibility" benefits, which means that a person will receive benefits before a final determination is made. To be eligible for this, a claimant's physician or healthcare provider must fill out form SSA-4814 certifying the degree to the disease has progressed. A person can receive presumptive benefits for six months while his or her case is being formally processed.

Social Security's definition of disability requires that a person have an impairment that will prevent him or her from working and would/or has prevented them from working for at least 12 months. In order to determine disability, Social Security follows a sequential evaluation process. "We start with someone who has a medically determined impairment," said Ms. McDonough. "The first two steps are to screen out. If the person is working, and making \$500 a month, then we wouldn't find them disabled no matter what their impairment is, because they still have the ability to work." In the second step, the agency determines how severe the impairment is and whether it impacts on any work-related activity. If it did not, a person would not be found to be disabled. At the third step, the disability examiner checks to see if the impairment meets the medical criterion in Social Security's listings of impairments. "We take a look at what residual functional capacity the person has left and after determining that, what kind of work the person can perform," advised Ms. McDonough. "If they can still do their former occupation, then we would find them not disabled. If they can't do that, we would look for other types of work that they could do." All adult applications are processed in this fashion.

In 1993, Social Security passed regulations that specifically address HIV. These provide standards for tests to identify an individual's diagnosis and list the manifestations of HIV and opportunistic diseases. There is also a functional standard, because HIV and AIDS can restrict and limit an individual's ability to take care of daily activities. "There's a certain amount of fatigue," said Ms. McDonough. "There's an inability to work because



you lose the ability to concentrate. You can't work at the same pace. And these factors are taken into consideration."

Claimants can appeal decisions. Reconsideration is done at the State Disability Determination Agency by a different group of people than the initial reviewers. In the next level of appeal, cases are brought before an administrative law judge. If denied at that level, a case can be brought to an appeals council; if that is denied, to district court. Social Security has a fast track for any terminally ill individual and those with AIDS get judicious handling of their case.

To be eligible for Social Security benefits a claimant has to be, or has to be expected to be, out of work for a year. Sometimes a claim will be filed by someone who goes into a period of remission or receives an opportunity to work. Ms. McDonough said she would counsel claimants not to return to work while a case is pending, because it could force Social Security to deny the case. It would be better to return to work after receipt of an award notice, because then the claimant would be eligible for a trial work period and their Title II benefits.

For further information, Ms. McDonough can be reached at 212-264-7293.

### **Discussion of Issues: participant questions and comments ("Q") and speaker responses ("A").**

Q About HIV cases and the Office of Civil Rights—I can understand from a humanistic standpoint why you would fast-track them, but what legal jurisdiction do you have?

A [Carter] We follow the money. In other words, where there is HHS funding, 99.9 percent of the time OCR has the jurisdiction to initiate a review and investigation.

Q You mentioned a memo issued on LEP [limited English proficiency]. If an agency funded by HHS has written literature, but not in "x" number of languages, would they be out of compliance? How far do you have to go?

A [Carter] It all depends. Equal access must be provided regardless of race, creed, color, or national origin. We've taken that to mean that facilities are required to provide materials that people can understand, based on the service area population. There is a numerical threshold, normally a certain percentage basis.

A [Morales] Sometimes it's difficult to give a blanket number. Every case has its own merits and we try to look at each individual case. Generally speaking, hospitals and/or clinics that have a service area in which 10 percent of the population speaks a language other than English have an obligation to provide materials in that language. The issue is to ensure that those persons have the same quality of access as everyone else has.

Q You opened your remarks by stating that there was a lack of interest in the EEO (Equal Employment Opportunities) arena. It was just a general statement about complacency. I see that going on across the country and I see some of the laws being repealed. What do you attribute that to?

A [Carter] Many people no longer believe that discrimination is an issue. [Safeguarding rights] has not been a high priority in recent years. The traditional civil rights organizations have moved their focus from education or housing to economic development. But it is important for us to put more focus on health access.

Q You said that with OCR you have 180 days to file a discrimination case. If someone doesn't know that, is there leeway with that time frame?

A [Carter] The time limitation can be waived under certain circumstances. There are divergent reasons why people don't file within the proper period of time. But when you get to a point when it's a year later, after the 180 days, litigation becomes tough. A lot of times the players have changed, memories get shorter, or the data no longer exists or has been distorted. So it gets tougher. But we do have the latitude to waive under certain circumstances.

Q I was wondering if rather than 180 days from the incident, it would be from when you learn that there's a violation. A good example is sexual harassment. If a person was sexually harassed over 180 days ago, but then they went to a sexual harassment workshop and they learned what constitutes it, and realized "oh, wow, I was sexually harassed." Can you seek a waiver, because you learned about the incident afterwards?

A [Morales] You can bring a complaint if it's within the 180 day period. If you live in New York City, the City Commission on Human Rights' administrative code section that deals with race or disability discrimination specifies a one-year period for filing complaints. If you bring a private civil action, you have a three-year period to bring a complaint without penalty.

If you feel you've been the victim of discrimination because of your disability at an entity that receives federal funding, then you should contact us. We'll assign an investigator who will investigate your allegations. In cases where we find there has been a provable act of discrimination, we will either try to negotiate a resolution of the claim, or if worse comes to worse, we'll begin with something that's known as "fund-termination proceedings," in which we look to terminate that employer or agency's federal funding. Ordinarily, that threat brings people into compliance. We rarely get fund termination proceedings in our offices, because just the threat of cutting off federal funding is enough to scare a facility into doing the right thing.

A [Carter] Complaints should be short and simple. We have found in workshops that people are concerned about filing; they worry that perhaps their English isn't good enough or they can't formulate the complaint. I advise folks to write just the way they would talk to me. Keep it simple and state the principal things. When did it happen. What happened. Witnesses. What the actual act of discrimination was. It's important when you talk to friends and colleagues from the organizations you represent to let them know that if they need assistance, they can always call and have someone assist them in writing a complaint form.



Q You said you haven't had a large number of cases of HIV/AIDS-related complaints. You mentioned that people go to the city agencies first or directly to court. Why?

A [Morales] The problem is that, oftentimes, people who are discriminated against want personal redress in the form of damages. Our statutory framework doesn't allow us to seek individual damages. We can seek redress of the problem itself, and we may be able to negotiate a resolution to this effect, but we can't order that someone be given personal damages.

Q What happens if a CBO (community-based organization) refuses to take an HIV infected or AIDS diagnosed client, due to, they claim, that there are too many clients already? And also, they don't make any referral?

A [Carter] On the surface, it would raise a concern with us, but it's one of those situations where I would need to secure more information. If I got that type of complaint, I would have to find out what their capacity is. Assuming that they have received and taken other persons with HIV or AIDS, it might not present a problem because it doesn't suggest that they have a restrictive admissions policy. It just may be a matter of capacity, that they may not be able to absorb another person.

Q I worked for the Division of Human Rights. I have investigated AIDS-related complaints. Our system is a little different from the federal system. We have a year for filing, rather than 180 days. Many funding streams require that you have linkages. So the first part of the problem may not have been a problem, if as in the example cited, the clinic was filled to capacity. But the problem you added was that they didn't refer the client to any other clinic either. Most of the federal funding streams have linkages in which there have to be referral systems, especially in New York State, where we've been trying to build continuum of care between the systems. So I would look into that aspect as well to see what they did.

Q With Social Security, what happens if a person has a long HIV illness and never gets tested, but waits until his or her T-cell count falls way below 200 and all of a sudden gets sick with PCP pneumonia and has to go into the hospital? The person has been working all this time, but all of a sudden he or she cannot work. What is the 12-month period you are talking about? Do you mean the person has to stop working for a year before he or she can apply?

A [McDonough] No. We expect that a person is going to be out of work. Part of the decision process in determining disability is not only to explore if the impairment is severe enough to be disabling, but also to ascertain if it meets the duration requirement. A person doesn't have to have already met it, but Social Security has to believe that the disability is going to last for 12 months. For example, if a person with a broken arm were to file with us, the healing time for a broken arm might be three months. We would not expect it to last 12 months.

I'm not advocating how life decisions should be made. But if you are an information provider for clients, you should tell them that for Title II (benefits based on the claimant's work history) purposes, if he or she has not yet been out of work for 12 months and returns to work before Social Security finishes adjudicating the case, we can't make the presumption that the illness is going to last 12 months. That's what the law says. Some individuals may be happier returning to work and not filing for disability. That's a life decision, but you should know what your options are.

Q Let's say that I don't know how long it will take a client to get well. What is the situation here? Does he go through a three step screening or impairments regulations?

A [McDonough] When a person files for SSI or Title II benefits, we'll take for granted that the person is not working if they have symptomatic HIV. For example, if they have PCP (pneumococcus pneumonia), they are awarded benefits because that meets the criteria. If they return to work for a trial work period under Title II, it would depend on how much money they earn whether benefits continue under SSI or not.

Q What's the normal processing time once a person who has been identified presents?

A [McDonough] The thing that takes the longest amount of time is collecting medical evidence. So if claimants can work with a health professional to expedite getting medical evidence, cases can be adjudicated in two weeks. Sometimes there is a problem if the evidence doesn't meet the criteria for severity. Sometimes we want to know more about the impairment from the clinic that a person attends. Does the evidence describe what the total symptoms are and how a person is reacting, or do we have to go after collateral evidence to find out what the person's daily activities are and how they function? Then processing takes longer. If a third party—an advocacy group, community group, whatever—can help collect this data, it speeds up processing the case.

Q Substance abuse—does Social Security pay benefits for that?

A [McDonough] Not if that is their only impairment. If the only reason a person can't work is because of addiction, then that's excluded from payment. If you're an addict and HIV-positive, and have HIV manifestations—it doesn't matter that you're an addict, you're entitled to benefits. But if addiction is your only disability, you're not eligible.

Q You said Social Security is complicated. Who informs the clients who come in? When someone who is sick is applying for Social Security, it's problematic to go through the system.

A [McDonough] The Social Security Administration is supposed to be an advocate for an individual—although with downsizing, no one gets serviced like they used to. We do try to do community outreach. We can help community organizations by educating them on the complexities of the program and teaching them how to assist us in taking the applications. Our doctors or medical relations staff can speak



to a community group's staff about what kind of medical evidence needs to be gathered. If you represent a community group you could get in touch with me and you could set up meetings for that type of outreach.

A [Carter] If you work for a community-based organizations and you would like to have someone come out and speak to your group, give us a call. If there's an institution that you believe is delaying or denying access to persons that you advocate on behalf of, call us.

Q This is the first time ever I've heard about the OCR. Every one should know what is happening, what their rights are. I'm from the Chinese American Planning Council and I'd like both of you to come in.

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### **Recommendations:**

- Publicize the issue of HIV discrimination and emphasize that this continues to be a critical civil rights issue.
- Reach out to those affected by HIV discrimination and help them understand their rights.
- Provide local community-based organizations and health facilities with literature on discrimination that can be distributed to clients and patients. Literature should be available in a variety of languages.
- Provide assistance to companies to help ensure that they are not in violation of civil rights statutes that pertain to individuals with HIV/AIDS.
- Develop strategies to eliminate barriers and ensure equal access to all HHS programs.
- Create a special office within Social Security to assist individuals with HIV/AIDS.
- Fund more community outreach on the issues of discrimination and assistance with Social Security claims.

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**Northeast & Caribbean Region**  
**HHS Community Meeting on HIV and AIDS:**  
**Confronting the Second Generation of the Epidemic**

## **Workgroups**

### **Workgroup F: HIV/AIDS and Medicaid HIV/AIDS and People over 50**

**Speakers:**

**Nilsa Guterrez, M.D., Health Care Financing Administration, Region II**  
**Michael Melendez, C.S.W., M.S.W., Health Care Financing Administration, Region II**  
**Carmen Sanchez, Administration on Aging, Region II**

**Facilitator:**

**Stephen Ritzel, SUNY Downstate Medical Center**

In brief: Workgroup F reviewed Special Needs Plans (SNPs) and what these will mean for people with HIV and AIDS under Medicaid Managed Care. Also examined was the problem of HIV/AIDS among people over 50. The Health Care Financing Administration (HCFA) was represented by Michael Melendez and Nilsa Guterrez, former head of the AIDS Institute. Carmen Sanchez presented on behalf of the Administration on Aging (AOA). In New York State, 11 counties, including New York City, are moving forward into Medicaid Managed Care. Under this program, individuals with HIV/AIDS will be eligible to participate in a SNP. Initially, enrollment in either a Medicaid Managed Care program or a SNP will be voluntary, but eventually, enrollment will be mandated. Both the state and federal governments are working hard to ensure that once enrollment begins, the process will work well and be consumer friendly.

AIDS among people over 50 is a growing concern. Estimates released by the National Institutes on Health show that while the number of new AIDS cases is declining among young persons, cases continue to climb among older adults by 10 percent or more annually. When HIV and AIDS prevention messages target only young audiences, an important group of individuals at risk of infection is ignored. Compounding the problem, physicians often do not discuss HIV and AIDS with their older patients.

The presentations of the speakers, and the ensuing discussions are presented more fully below. (Note: these are edited, both because of space limitations and because some of the discussion was inaudible on the tape. In the discussion section "Q" indicates comments from workgroup participants; "A" indicates feedback from speakers.)

**Speaker: Michael Melendez, C.S.W., M.S.W., Health Care Financing**

**Administration**

Dr. Guiterrez gave a brief introduction, then turned the discussion over to Mr. Melendez, who discussed Medicaid Managed Care Plans and Special Needs Plans (SNPs). Under Medicaid Managed Care, SNPs will be created to provide a comprehensive system of care to those with serious illnesses. In New York State, some 11 counties have already begun to enroll beneficiaries into Medicaid Managed Care. New York City has recently completed its readiness review and is awaiting federal approval to begin enrollment.

Issues addressed in the readiness review include accounting systems, benefits, access to service, provider capacity, the enrollment/dis-enrollment process for beneficiaries; complaint and appeal rights; quality assurance measures and performance monitoring initiatives. A thorough evaluation was done to ensure that Americans with Disabilities Act protections are in place and that there are safeguards relating to those protections. A key piece is to make sure that marketing practices are ethical. If HCFA determines that a program has problems, it can stop the process at any point until the problems are corrected.

Part of the conditions that HCFA established in order for a state to participate in Medicaid Managed Care is that there be a "Milestone Process" in place to develop Special Needs Plans. The Milestone Process details the steps necessary before a SNP can begin enrolling participants. Part of this process is the development, review, and public release of a competitive RFA (Request for Announcement) for both an HIV/AIDS and a Mental Health SNP. The RFP (Request for Proposal) development process has to be completed before it can be released to groups. The AIDS Institute has held a number of focus groups over the last several years and is developing an RFA incorporating suggestions obtained from the focus groups and the papers it has received.

**Speaker: Carmen Sanchez, Administration on Aging**

Ms. Sanchez provided background on the Administration on Aging, explaining that, in her experience, not many elderly people know about the agency. AOA is the only federal agency devoted exclusively to the concerns of America's older population. Its history can be traced back to 1965, when it was enacted as part of the Johnson Administration's



Great Society Initiative.

AOA's mission is to remove barriers to economic and personal independence for all older adults and to ensure the availability of appropriate services for older persons in need. It does so through a network that encompasses 670 area agencies on aging, 130 Native American tribal organizations, and approximately 27,000 local service providers.

Ms. Sanchez discussed HIV and those over 50. Persons aged 50 and older account for about 11 percent of all known AIDS cases. More alarming are the estimates released by the National Institutes on Health that demonstrate that, while the number of new AIDS cases reported annually is declining among young persons, cases continue to climb among older adults by 10 percent or more annually. "Those are staggering numbers," said Ms. Sanchez. The problem will likely only grow worse as America's population ages. The number of people over 50 is expected to double within the next 50 years.

Not only do misdiagnosed and undertreated HIV infections affect the morbidity and survival of older patients, they increase the risk of transmission. Although homosexual/bisexual contact and injection drug use remain the primary means by which HIV is transmitted among all age groups, heterosexual transmission of HIV is increasing rapidly in persons who are over 50. A study of hospitalized HIV infected patients who are 50 found that the infection was transmitted through sexual intercourse in 38 percent of cases, through drug injection use in 16 percent, and from blood transfusion in 9 percent. "As practitioners we have to be prepared to meet the challenges of the changing HIV landscape both demographically and clinically," advised Ms. Sanchez.

Of those infected by sexual contact, heterosexual contact was the route of transmission in 14.5 percent of cases. Ms. Sanchez said this contradicts the commonly held belief that older persons acquire HIV infection primarily through infected blood, and that they are not sexually active. Although the occurrence of sexual activity may decrease, the majority of individuals age 50-plus remain sexually active.

Ms. Sanchez reviewed two National AIDS Behavioral Surveys, conducted in 1990 and 1991. Both found that 10 percent of Americans aged 50 or older had at least one risk factor for HIV infection. The most common risk factor was multiple sex partners.

What this data conveys, said Ms. Sanchez, is that no person with symptoms of HIV should be presumed to be beyond suspicion solely because of age or apparent behavior. Health-care providers should be concerned about older adults with no

identifiable or documented transmission factors. According to data from the CDC, 26 percent of all cases of HIV/AIDS in the over-fifty population arise from unidentified transmission factors.

From this, said Ms. Sanchez, it can be concluded that there is a lack of information among older individuals with regard to risk factors for HIV. This is especially true for older women, who may be at high risk of acquiring HIV from an infected partner because of atrophy of the vagina, which raises the potential of viral transmission through intercourse. Furthermore, many older people disregard the need for condoms because they associate condoms solely with pregnancy prevention. Many older persons became sexually active in the pre-AIDS era, when most sexually transmitted diseases were easily cured with antibiotics.

When HIV/AIDS prevention efforts are directed mainly towards younger persons, they exclude a growing group of individuals at risk of infection. "We need to look at our educational handouts, posters, and public service announcements, and make sure that the elderly are represented," said Ms. Sanchez. "People have the belief that after 50 you stop having sex. It's not true."

It also appears that information about risk for HIV is not routinely pursued with patients beyond a certain age. HIV prevention efforts can be successful only if physicians seek out risk behavior information regardless of a patient's age and whether the patient appears to have had experiences that would place them at risk. An accurate and thorough sexual history should be integrated into a general assessment. Sexual history should be taken in a simple and understandable way. The questions should elicit information about whether the patient has had sex with men, women, or both. Does the patient take any precautions against disease? If so, what are they? And if not, why not? Has he or she ever had any sexually transmitted diseases? Does he or she use injected drugs or is there needle sharing? If there is, how are the "works" cleaned?

"All these questions have to be integrated into a general assessment, because we know that the elderly are involved in risky behavior," concluded Ms. Sanchez.

### **Discussion of Issues: participant questions and comments ("Q") and speaker responses ("A").**

Q     Regarding the RFA (Request for Announcement) for SNPs (Special Needs Plans):

We were required to submit our suggestions in writing by February 13 of last year (1998), and were told that we would hear what the RFA was going to be by May 1, then June, July, September 1, and then after the elections. Now we're almost back to a year since we were required to submit that. We've heard nothing about what the RFA is going to contain, and if any attention has been paid to our recommendations.

A [Melendez] We are waiting for the New York State Department of Health and the AIDS Institute to get back to HCFA as to what stage the RFA is in. We haven't heard yet.

Q We have been part of the "Milestone Process" in terms of looking at the application to see that it meets all of the criteria. We have a check-off list of things to include. But we don't know who has copies or how our recommendations have been used.

A [Melendez] HCFA has had the opportunity to review the information that the task force developed and submitted. We don't have individual agencies' comments. We have not seen the RFA. Before approval is given for the RFA to be issued and contracts to be signed, HCFA needs to approve the RFA. Another key piece in the development of the RFA is the benefits package that is to be available and what the rates are that will be paid to the SNPs. There must also be developed a stop-loss reinsurance program for SNPs, including the methodology for determining the stop-loss level.

Q What does that mean?

A [Melendez] You have a capitated rate for payment. If a group or hospital provides services over that rate, they will incur a loss. They have to develop a system to make sure these costs do not bankrupt their plan and they have the ability to apply and purchase stop-loss insurance.



Q It's insurance on the insurance.

A [Melendez] Right. Like most insurance companies, they have insurance to cover their insurance. This has to be addressed in the RFA. Because this is a new endeavor, we want to make sure that all bases are covered before we approve a program to go forward.

In New York City, the process is a little different from the rest of the State. New York State is hiring an enrollment broker to educate people about Medicaid managed care and what their options are and how the program works. The AIDS Institute, as part of the Milestone Initiative, must develop a specific AIDS education and outreach program to educate people about SNPs and their options—which are either to enroll in a SNP or stay in fee-for-service. There will be two processes—a voluntary SNP process and then a mandatory process. Potential enrollees have to be educated about this entire process, its time frame, and their options. The Maximus Group will be enrolling people with HIV into a SNP once the program begins. However, the AIDS Institute must have an education program and not rely on Maximus to do its education.

Other requirements include detailed computer tracking systems to track enrollments, dis-enrollments, services provided, fees, and medical services. They also have to ensure that this system provides for confidentiality. Once New York City gets permission to go “live,” an individual with HIV/AIDS can remain fee-for-service or voluntarily enroll in a managed care plan, or enroll in a voluntary SNP. It all has to be clearly spelled out up front in the policy and procedure manual—how enrollees can opt for this benefit or not, how they can seek an exemption from enrolling in Medicaid Managed Care. We want a process that is easily understood by the consumers.

Q Will fee-for-service Medicaid always be an option?

A [Melendez] It will be an option until the SNPs become mandatory. Once the RFA is out people will have three choices: voluntary enrollment in a SNP, remaining fee-for-service, or joining a mainstream managed care plan. Once SNPs goes mandatory, they then will have two options: mainstream plan or join a SNP.

Q What do you see as the time frame?

A [Melendez] It's unclear. HCFA has finished the readiness review and we are completing our final review of the documents that we asked for as a result of our onsite visit. We are now in the process of writing our report to submit to our central office for approval before we release it to the state.

Q From the viewpoint of a PWA (Person with AIDS), I'm very involved with this. I've been to a lot of hearings in the state on the SNPs, and unfortunately, a lot of agencies in the city are giving out wrong information. Many people who have HIV are joining Medicaid Managed Care under the wrong pretense. They are given the wrong information and they think they have to sign up now. The message is not out there *clearly* that people with HIV do not have to go into any mandatory Medicaid Managed Care program at this time. And this is a question that many people who are in advocacy and on committees and planning councils keep asking the state. What is the realistic time frame for when people living with HIV will be required to go onto mandatory managed care?

A [Melendez] They will have three options during the first year while the SNPs are voluntary: Fee-for-service, a voluntary SNP, or enrolling in a mainstream managed care plan. Once the SNPs become mandatory, and there will be an announcement made that it will be mandatory, they can either join a SNP or a managed care plan. They will no longer be able to be in fee-for-service.

Q I hate to be a pest, but we've been trying to get the right information for over a year, and it keeps on changing. So I want to nail you down on one thing. If this started tomorrow, it would be another year before somebody would have to make a choice?

A [Melendez] Someone would have to make a choice between the three. When Maximus sends a brochure, if the person is HIV positive, he or she will have to make a decision to enroll in a mainstream plan or a SNP. The state can identify people who are HIV positive by certain services they receive, and these individuals

won't be auto-assigned to a plan. However, individuals who are not identified in the system as HIV positive will be auto-assigned if they have not selected a plan within 60 days, unless they fill out a form saying "I want to be exempt."

Q People have been very afraid and think they have to join. I want to tell people that no, all you have to do is let the appropriate parties know that you are HIV positive and you don't have to join.

Q Case managers have also been known to tell a client, "This is going to be mandatory real soon, you might as well do it now."

A [Guterrez] Many of the community-based health care facilities are now obligated to develop contracts with managed care plans for people with Medicaid. It's not mandatory yet, but the process has already started. Basically what they are doing is trying to capture the market. The assumption is that it's mandatory. But it's not, it's voluntary. If you're telling me that you have gone to a health center and they have told you that you have to become part of a managed care plan to continue to get care there, that is misinformation. It's inappropriate and it borders on illegal.

Q For PWAs, there is confusion and fear because people who did go into managed care are having trouble accessing care. They're having to wait for months to get appointments to have MRIs, to see specialty clinics. We're concerned in the community. Is this going to be the same problem—that people who have emergencies with HIV have trouble accessing care? We can't wait weeks and months for appointments.

A [Ritzel] Have they been complaining to appropriate sources, such as the New York City Department of Health? An administrative complaint must be responded to within 45 days. If there's a risk to your health, DOH must respond in 24 to 48 hours.



A [Guterrez] You're always going to find abuse in any health-care facility. What we tried to do with the Special Needs Planning was to include the kinds of clinical problems and emergencies PWAs have and to insist, because of the nature of the disease, that agencies respond differently than they would in a commercial plan. That is why, in part, it's called the Special Needs Plan. What we wanted to do is set up not just a benefits package, but an attitude that is fundamentally different on the part of the managed care plans about how they are supposed to respond to people and patients with HIV disease. Which is, if you have a medical emergency, there should be absolutely no impediment to being seen in the emergency room.

Of course, they have to include a grievance process, which we hope would only be something of last resort, because we assume that physicians involved in managing people with HIV disease would comply with appropriate standards of care. We have insisted that the AIDS Institute have the right to audit managed care plans to measure quality assurance and ensure that state-of-the-art treatment is offered. That's a major leap, but that's part of the program, and that's what makes the Special Needs Plan so different and so difficult for commercial plans to accept. We're essentially rewriting the rules about how they go about the business of managing patients.

Q There's a problem we're seeing at the Momentum AIDS Project. The Mayor is making it difficult for people to stay on Medicaid. I've had three clients in the last two months on Medicaid who have been on triple drug therapy. Their Medicaid has been denied, and now they can't access triple drug treatment. They can't get anything. They don't qualify for ADAP (AIDS Drug Assistance Program).

Q I'd like to see multiple points of contact. The focus should be not just on hospitals and clinics. Programs like Momentum, which has providers in the field, should be incorporated into Special Needs Plans. A recommendation would be that SNPs wouldn't just be an interface between HIV-infected clients and a clinic

or a hospital or health provider, but would interface in multiple ways. For example, the community-based organizations would be part of SNPs, and the big players would be forced to work with them. There is no motivation for them to do so at this point.

A [Guterrez] The whole purpose of the Special Needs Plan is to bring nonmedical community-based organizations in, and this is the problem.

Q I'd like to change the name from "managed care" to "managed profit." Then we'll know what we're dealing with. I would really like to see the process of misleading the public criminalized. Because what we see in Momentum when we deal with our clients who are very poor is, that when people want to get rid them, they just throw them out the door.

Q My concern is the need to have culturally-sensitive training for all staff members, because you are dealing with multiple complex issues.

Q Education doesn't seem to change behavior. There has to be accountability in terms of letting clients know how to deal with the patient ombudsman, how to report staff for unprofessional conduct, how to take licenses away from staff, how to deal with personal liability issues. Staff has to understand that they are accountable to their patients.

Q The appeals process for service denial has me a bit worried. What kind of safeguards do you have for when services are denied? Because basically, these companies are only making money by denying services.

A [Guterrez] The only safeguard is the complaint process. That's the internal complaint process within the managed care plan. The plan description has to provide information so that people know that in the absence of any resolution, they can come directly to the federal agency to file a complaint.

- A [Melendez] I want to answer that question as it relates to SNPs. We're in the process now of finalizing and negotiating certain pieces with the state on the internal managed care organization complaint system. If it does not bring the client to what the client wants or needs, clients must have the right to a fair hearing.
- Q You mentioned the word ombudsmen before. GMHC (Gay Men's Health Crisis) had an ombudsmen for many years and then, due to lack of funding, they closed that office down. I was at a meeting with a representative from HRSA (Health Resources and Services Administration) and other members of the executive committee of the PWA Advisory Group of the New York City HIV Planning Council. We said, "We need to have an ombudsman office to help people with HIV who are having serious problems." The HRSA representative responded by saying that since CBOs (community-based organizations) are funded by the Ryan White CARE Act for case management, it is the case manager's responsibility to deal with problems. She totally refused to open up an ombudsmen office for PWAs. With PWAs you are talking about people who are dealing with so many problems. Now we're throwing on them grievance procedures. Many people with HIV are not in any condition to start filing grievance procedures. And are these CBOs going to sit down and do it for them? We don't know that. I don't see support coming from the CBOs.
- Q The problem with CBOs is that they are understaffed. That's why they can't deal with that too thoroughly.
- Q That doesn't help the person who is there in the center. These answers are insufficient. You don't have the energy if you're laid out with this disease. And I do have AIDS, full-blown, have had it for awhile. I don't have the time or the patience for this. I don't have the energy to get up and fight most of the time.
- Q If the SNPs are supposed to provide not just medical services but a whole continuum of care that includes case management and social services, it should be absolutely mandatory that they provide adequate case management at the time of



involuntary dis-enrollment. That is, when a person is found ineligible for Medicaid, that that person is linked up with adequate services, especially medically. Make sure that you don't have these cases where, if your Medicaid is cut off today, immediately you're not part of the SNP, so you don't have your medication and you are off on your own. It should be required that a person is set up with a case manager from the SNP to make sure they are enrolled in ADAP (AIDS Drug Assistance Program) and that their medications can continue. If you don't provide that, then you're not in the health care business, you're in the profit business.

Q With day treatment programs, most of the clients are substance users. If you think for one minute that any of those clients know the first thing about Medicaid Managed Care you can forget about it right now. My concern is that a lot of the day care programs are going to become primary care centers on Medicaid Managed Care and these people are going to be signed up without knowing a damn thing about what it's all about. They're not training them, not teaching them, not telling them a thing about it. They're just using them. My question is, what happened to the State's Bill of Rights for Patients? Going back to your problems with grievance procedures: I think grievance procedures should include a sensitive treatment of patients.

A [Melendez] We don't think day treatment programs are going to become principle providers. The physicians themselves will be the principal provider for individuals involved in the day treatment program. A day treatment program is set up so that there is a clinical component. They are the ones who provide acute care if you become ill while you're in the day treatment program, or they appropriately assess you and refer you back to your physician and/or to a hospital. I wanted to clarify that, because you made a statement that is not accurate.

Q Then I have to clarify with you the fact that they are making the statement, those centers for care, that they are going to be a primary care center.

A [Guterrez] They are going to be part of the Special Needs Plan. That's different. In other words, the whole purpose of the Special Needs Plan was to do one thing—to preserve the providers who had all the experience in HIV care, treatment, and support services in the arena of continuing to provide services, especially when you had a mandatory program. When Governor Pataki became governor, the priority of the health department was to institute Medicaid Managed Care within one year, without thinking about people in HIV treatment programs or those with mental illnesses or special conditions.

I want you to understand what happened when we were challenged and had to come up with a game plan very quickly. When we conceptualized it, we said the whole purpose of this is to preserve the expertise and make sure that they [the care centers] have a fundamental role in service delivery within Medicaid Managed Care. It's considered one sector within that continuum of care, but they would not become the primary care provider. So if they are informing you about that, we've got more trouble than what we think we do. If that's what's going on.

Q There's a new situation with the over-50 that has to be addressed concerning Viagra. What is happening is that you have older men who haven't had an erection in 20 years. Suddenly they have an erection for 24 hours, they want to go have sex. But they don't put a condom on because they feel the erection will be lost. So they're going down in the city and picking up sex workers, male or female, and contracting new cases of HIV. We see this happening now in the over-fifty population and there's a very big concern about this.

Q At my agency, 40 percent of our clients over 45-years old are HIV positive. A lot of the cases are from people who were diagnosed 10 years ago, but what's happened is now they're becoming older. And it's not being addressed. Those numbers will double and triple in the next five years.

Q I want the data and all the NIH studies that have been funded. I want the data broken out, over 50, under 50. I want to know, is there more depression,

decreased coping? I want all funded research to break it out. Are there clinical differences? I want the researchers to report it in their publications. I want to pick up a *JAMA (Journal of the American Medical Association)* article, and I don't want to just look at ages 25-44. I want the age broken out by the researchers when they report their findings.

Q The recommendation is to get the Office of Epidemiology within the City Health Department to break out its data by geo mapping and age. Do it for over the age of 50. You can do it in increments of 5 years, and publish it as a DOH publication within a certain time frame. I've been asking these questions for years.

Q There are issues in the Latino community [about age and sex]. Tell a 70 year old, "You should start using condoms," and they're going to tell you, "So what? I don't have many years left anyway. I'm going to go out and have fun." To change the male Latino behavior is very hard. I'm the director of a senior center, and I would like to see a peer support group for seniors. Now, the situation about Viagra: I have a senior who was happy like hell to get the Viagra. Went out. Did what he was going to do, and came back to me six months later and he was HIV positive. Now I have women coming to my office for the female Viagra. And I'm scared to death of that because women are saying, "Well if my husband can do it, I can do it too." And they're sharing partners. It's amazing the behavior, what this medication has changed.

I would also like to see an after-care program for seniors who are grandparents who have children that have died from this illness and who are now raising their grandchildren. There's no after-care program. We have hardship situations where grandparents are taking in grandchildren, and they don't have the stamina.

XX



## **Recommendations:**

### HIV/AIDS and people over 50:

- Track data trends and clinical information for 50-plus populations. There should be research on clinical differences that may affect this age group. Provide geo maps.
- Agencies should publish, on a regular basis, data concerning age and other specific characteristics.
- Establish peer support groups and after-care programs for elderly. These should be linguistically competent.
- Dose adj./interactions protocols are needed.
- Increased research on the above areas is necessary.

### SNPs (Special Needs Plans):

- Develop multifaceted linkages that cut across various types of providers.
- Education with accountability about sensitivity towards patients and appropriate staff behaviors in care and provision of services is necessary.
- Ensure that there is flexibility in the appeals process (e.g., provide safeguards for disputed cases).
- Develop fair and equitable grievance procedures.
- Measure care outcomes: Develop standards using focus groups/forums.
- Case management should be linked with adequate care.
- For day care treatment, develop a Patient Bill of Rights.



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# GLOSSARY





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**Northeast & Caribbean Region**  
**HHS Community Meeting on HIV and AIDS:**  
**Confronting the Second Generation of the Epidemic**

## **Glossary**

**ACF** -Administration for Children and Families

**ADA**-Americans with Disabilities Act

**ADAP**-AIDS Drug Assistance Program

**AETC** -AIDS Education and Training Center

**AOA** -Administration on Aging

**CARE Act** -See Ryan White CARE Act

**CBOs**-Community-based organizations

**CDC**-Centers for Disease Control and Prevention

**Congressional Black Caucus or CBC Initiative**-\$156 million authorized by the Congressional Black Caucus in Fiscal Year 1999 to address AIDS in African American and other minority communities

**CPCRA**-Community Programs for Clinical Research on AIDS

**CPG**-Community Planning Group

**EEOC**-Equal Employment Opportunities Commission

**EMA**-Emergency Medical Area

**FDA**-Food and Drug Administration

**FY**-Fiscal year

**HCFA**-Health Care Financing Administration

**HHS**-U.S. Department of Health and Human Services

**HBCUs**-Historically Black Colleges and Universities

**HRSA**-Health Resources and Services Administration

**LEP**-Limited English Proficiency

**MHRA**-Medical and Health Research Association

**NHSC**-National Health Service Corps

**NIAID**-National Institute of Allergies and Infectious Diseases

**NRMOs**-National and regional minority organizations

**OASAS**-(New York State) Office of Substance Abuse and Alcoholism Services

**OCR**-Office for Civil Rights

**OMH**-(New York State) Office of Mental Health

**OMH, Region II**-Public Health Service Office of Minority Health

**OWH-Region II**-Public Health Services Office on Women's Health

**PPG**-Prevention Planning Group

**Program Announcement 704**-The CDC's funding announcement #704, which provides funding directly to CBOs to deliver HIV prevention services

**PWA**-Person with AIDS

**Region II**-Region II of the Department of Health and Human Services, Region which encompasses New York, New Jersey, Puerto Rico, and the U.S. Virgin Islands

**RFA**-Request for Announcement

**RFP**-Request for Proposals

**Ryan White or Ryan White CARE Act**-Federal legislation passed in 1990 to provide care, treatment, and social services to people living with HIV/AIDS

**SAMHSA**-Substance Abuse and Mental Health Services Administration

**SNPs**-Special Needs Plans

**SPNS**-Special Projects of National Significance



**SSD**-Social Security Disability

**SSI**-Social Security Insurance

**STDs**-Sexually-transmitted diseases

**TA**-Technical assistance

**TB**-Tuberculosis

**Title I**-The section of the Ryan White CARE Act that provides grants to eligible metropolitan areas

**Title II**-The section of the Ryan White CARE Act that funds grants to the states, the District of Columbia, and a number of territories, including Puerto Rico, the Virgin Islands, and Guam. Also funds the AIDS Drug Assistance Program

**Title III**-The section of the Ryan White CARE Act that funds community-based programs and intervention services

**Title IV**-The section of the Ryan White CARE Act that funds pediatric and clinical research centers



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# APPENDIX





**HHS COMMUNITY MEETING ON HIV/AIDS:  
CONFRONTING THE SECOND GENERATION OF THE EPIDEMIC**

**AGENDA**

**January 14, 1999      8:00am - 5:00pm  
SUNY Health Science Center at Brooklyn**

**8:00am - 8:30am      Registration/Continental Breakfast**

**8:30am - 9:00am      Welcome/Introduction**

Eugene Feigelson, MD  
President, SUNY Health Science Center at Brooklyn

Alison E. Greene  
Regional Director, Department of Health and Human Services  
Region II

**9:00am - 10:15am      Plenary Panel:  
Department of Health and Human Services (HHS) Major  
Program Initiatives in HIV/AIDS and Opportunities for  
Community Partnership**

Panelists:

- Sam Dooley, MD  
Chief, Community Assistance Planning & National  
Partners Branch, Division of HIV/AIDS Prevention,  
Centers for Disease Control and Prevention
- Douglas H. Morgan, MPA  
Director, Division of Service Systems, HIV/AIDS Bureau,  
Health Resources and Services Administration
- Lucy Perez, MD  
Director, Office of Medical & Clinical Affairs, Center for  
Substance Abuse Prevention, Substance Abuse and  
Mental Health Services Administration

- Eric Goosby, MD  
Director, National HIV/AIDS  
Policy Office
- Marsha Martin, DSW  
Special Assistant to Secretary,  
Department of Health and Human  
Services
- Moderator: Alison E. Greene

**10:15am-10:30am    Break**

**10:30am-12:00pm    Public Comment**

**12:00pm - 1:00pm    Lunch**

**1:15pm - 3:00pm    Work Groups (6) - HHS HIV/AIDS-  
related activities with feedback and  
recommendations from participants**

***Work Group A***

***HIV/AIDS Care***

Douglas H. Morgan, MPA  
Health Resources and Services  
Administration, HIV/AIDS Bureau

***Children and Families***

Barbara Andrews Agency for Children and  
Families, External Affairs

***Facilitator:*** Roberta Holder-Mosley

Health Resources and Services  
Administration, NY Field Office

### ***Work Group B***

#### ***HIV Prevention + Education***

Samuel Taveras, MPH

Centers for Disease Control, Division of HIV/AIDS Prevention

#### ***Women + HIV/AIDS***

Sandra Estepa Public Health Service Region II, Office on  
Women's Health

#### ***Facilitator:***

Dorothy Gunter

Centers for Disease Control, Division of HIV/AIDS Prevention

### ***Workgroup C***

#### ***HIV/AIDS + Substance Use***

Lucy Perez, MD

Substance Abuse and Mental Health Services Administration, Center  
for Substance Abuse Prevention

Marty Bond

Substance Abuse and Mental Health Services Administration, Center  
for Substance Abuse Prevention

#### ***Minorities + HIV/AIDS***

Claude Colimon

Public Health Service Region II, Office of Minority Health

#### ***Facilitator:***

### ***Workgroup D***

#### ***HIV/AIDS Clinical Trials***

Deborah G. Katz, MSRN

National Institutes of Health, NIAID, Division of AIDS

#### ***AIDS Treatment***

Richard Klein

Food and Drug Administration

#### ***Facilitator:***

Dilcia Granville, MSW

Food and Drug Administration, Brooklyn Regional Office

### ***Work Group E***

#### ***Discrimination Concerns***

Michael R. Carter  
Office for Civil Rights

Fernando Morales  
Office of General Counsel

#### ***Social Security Benefits***

Angela McDonough  
Social Security Administration, Social Insurance Disability Program

#### ***Facilitator:***

### ***Work Group F***

#### ***HIV/AIDS & Medicaid***

Nilsa Gutierrez, MD  
Health Care Financing Administration

Michael Melendez, CSW, MSW  
Health Care Financing Administration

#### ***HIV/AIDS & People Over 50***

Carmen Sanchez  
Administration on Aging

#### ***Facilitator:***

<b>3:00pm - 3:15pm</b>	<b>Break</b>
<b>3:15pm - 4:00pm</b>	<b>Work Groups reconvene and summarize recommendations</b>
<b>4:15pm - 5:00pm</b>	<b>Plenary Session - reports from work groups</b>
<b>5:00pm</b>	<b>Adjournment</b>

~Continental breakfast, lunch and light refreshments will be provided~



**Planning Committee  
HHS Regional AIDS Work Group**

**NAME**

Michael Carter  
Office of Civil Rights

Jim Colangelo  
Administration for Children & Families

Sandra Estepa  
Public Health Service

Dilcia Granville  
Food & Drug Administration

Dr. Nilsa Gutierrez  
Health Care Financing Administration

Michael Melendez  
Health Care Financing Administration

Roberta Holder-Mosley  
Health Resources & Services Administration

Fernando Morales  
Office of General Counsel

Carmen Sanchez  
Administration on Aging

Annette Ervin  
Social Security Administration



**HHS COMMUNITY MEETING HIV/AIDS:**  
**Confronting the Second Generation of the Epidemic**

**PARTICIPANT'S QUESTIONNAIRE**

1. Which of the following HHS (Department of Health and Human Services) agencies are you familiar with: (check all that apply)

☐ HRSA: Health Resources and Services Administration  
☐ HCFA: Health Care Financing Administration  
☐ CDC: Centers for Disease Control and Prevention  
☐ FDA: Food and Drug Administration  
☐ NIH: National Institutes of Health  
☐ OCR: Office of Civil Rights  
☐ ACF: Administration for Children and Families  
☐ AOA: Administration on Aging  
☐ IHS: Indian Health Service  
☐ AHCPR: Agency for Health Care Policy and Research  
☐ SAMHSA: Substance Abuse and Mental Health Services  
Administration  
☐ PHS: Public Health Service

2. Which HHS HIV/AIDS program has worked well in your community?
3. What unmet need do you see that HHS HIV/AIDS programs should address?
4. What are your recommendations on ways HHS can improve HIV/AIDS prevention for your community?
5. What are your recommendations on ways HHS can enhance HIV/AIDS care and treatment for your community?
6. What are your recommendations on ways HHS can strengthen HIV/AIDS research for your community?

7. Use the following point system to rate each of the following statements or questions.

<b>Excellent</b>	<b>Good</b>	<b>Average</b>	<b>Fair</b>	<b>Poor</b>
<b>5</b>	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>

- How helpful was the information provided at the HHS Community Meeting on HIV/AIDS?
- Overall, speakers were relevant and address pertinent topics.
- Overall, work groups were relevant and addressed pertinent topics.
- The HHS Community Meeting on HIV/AIDS provided me with knowledge that I can apply to my job.
- The handouts and visual aids were appropriate.
- The level of individual and group participation was appropriate.
- How would you rate the site of the HHS Community Meeting on HIV/AIDS?

8. Additional comments:



<p>Appendix E</p> <p>Responses to Participant's Questionnaire</p>
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### HHS Community Meeting HIV/AIDS: Confronting the Second Generation of the Epidemic Survey Analysis

1. Which of the following HHS (Department of Health and Human Services) agencies are you familiar with: (check all that apply)

Respondents	Agency
26	HRSA: Health Resources and Services Administration
13	HCFA: Health Care Financing Administration
30	CDC: Centers for Disease Control and Prevention
25	FDA: Food and Drug Administration
25	NIH: National Institutes of Health
6	OCR: Office of Civil Rights
14	ACF: Administration for Children and Families
12	AOA: Administration on Aging
2	IHS: Indian Health Service
4	AHCPR: Agency for Health Care Policy and Research
14	SAMHSA: Substance Abuse and Mental Health Services Administration
17	PHS: Public Health Service

Which HHS/AIDS program has worked well in your community?

Government agencies, funded programs:

- ADAP+
- CDC (Centers for Disease Control) (5 respondents)
- CDC 794 cultural and language grant (2 respondents)
- HRSA (Health Resources and Services Administration) (2 respondents)
- NIH (National Institutes of Health)
- Ryan White Contributes to ADAP
- Ryan White Foundation
- Ryan White Title I
- Ryan White Title I, III, IV
- PHS (Public Health Service)

Types of Programs:

- Food programs
- Identifying infected women and children programs
- HIV Prevention Community Planning (2 respondents)
- HIV Consortium and early intervention
- Needle exchange
- MHRA case management in CBOs

Specific community programs:

- Discipleship Outreach Organization
- Momentum AIDS Project (2 respondents)

Additional Comments:

- No program: there is insufficient funding to address all the issues they treat HIV/AIDS but not sexual abuse or housing.
- Afro-American disparage.
- Systems not geared towards needs, lack infrastructure, and stability with the community.
- Food pantries lack funding.
- In New Jersey, AIDS has become a way to expand client base, but needle exchange remains forbidden by Governor Whitman and the state's attorney general.

3. What unmet need do you see that HHS HIV/AIDS programs should address?

- Innovative programs engaging and retaining substance abusers in care.
- Increase available hospital services to usually treated as the forgotten. @
- Untraditional access.
- More outreach and community-level intervention, not only with the CBOs but also outreach to individuals and families.
- Community-level information dissemination on prevention, treatment, and care.
- Community activities.
- Needle exchange (3 respondents).
- Prevention program funding.
- Prevention reform for the undocumented.
- Adolescent prevention (3 respondents)
- Affected pre-adolescent children.
- Adolescent integrated services, rather than addressing only HIV/AIDS; general at-risk adolescent health services.
- Save haven homes.
- Neighborhood funding and services with youth campaigns.
- Care for families.
- Infected elderly over 50.
- Bilingual services.
- Monolingual and color communities.
- Harm reduction.
- Zoning codes.
- HUD safe housing allocations.
- Individual and family housing.
- Free clinics.
- Increase funding for medications.
- Nutrition for HIV/AIDS patients.
- Allocate money for direct service agencies.
- Mental health (3 respondents)

- Additional staff funding, especially for social workers.
- Sexual abuse and domestic violence issues.
- Sensitive incarcerated prevention and treatment (esp. juveniles).
- Data collection.
- Fund new reporting mandates regarding Ryan White.
- HRSA to ensure Ryan White funding in New York City is allocated.
- Computers, computer operators, vans, and money.
- Clinical trials.
- Case identification for women who do not receive prenatal care.
- Streamlining services.
- Ryan White funds to cover unmet needs. I.e., home health aide hours which are not enough provided for by current Medicaid reimbursement.
- Case management reform for Chinese immigrant women and elderly.
- HIV 750.
- Specific maintenance of HIV-negative women.

**4. What are your recommendations on ways HHS can improve HIV/AIDS prevention for your community?**

- Grants program development for HIV+
- HHS should take a closer look at community-level CBOs' funding and get reports on plans to evaluate those services
- Increase adolescent outreach; sponsor adolescent-specific prevention programs; increase funding for peer educators in adolescent programs.
- Identify prevention and mental health issues.
- Develop prevention campaigns with big corporations (Nike, Gap, etc.)
- Work with churches.
- There should be holistic, comprehensive community approaches that connect HIV/AIDS to STDs, family planning, and all other issues.
- Increase focus groups with increased input from infected and affected communities.
- There should be outreach to middle-aged and older adults.
- The New York City administration is hostile towards education: Get real about education!
- There should be peer education in areas not reached by traditional means.
- Provide education in the form of more meetings with actual case individuals demonstrating comprehension and feedback to the actual material taught.
- Adolescent primary prevention in minority communities including gay youth.
- Street outreach; development of community lay leaders; investment in local agencies with history of consistency in communities and credibility.
- Fund general health-care centers with linkages with auxiliary services (i.e., mental health, domestic violence, job training, etc.)
- Use HIV as a lens by which we view everything/everyone holistically to promote mental, physical, and emotional health care.
- Funding needs to keep pace with real research. The NIH's HIV 1997 consensus has knowledge and strategies, but there are few ways to fund them in the South Bronx.
- There should be more abstinence education in schools, churches, and adult senior centers, along with resource information. Ask sexual addiction questions.
- Testing/education; outreach; peer education; stipends for peer education; more available information on support groups: MICA/substance abuse/children and families/affected and infected.
- Flexibility of eligibility for prevention activities, especially in Trenton, New Jersey and



Mercer County. Prevention activities can be broadened to include areas bordering Trenton; populations are more mobile than they used to be.

- Needle exchange in New Jersey.
- More risk reduction and prevention funding.
- More cultural and language-specific programs: no one single organization can serve all subcultures, especially Asian groups.
- Support community-based organizations. Carry out prevention work in culturally-sensitive manner. Support CBO-developed strategies even if their numbers are not that high: It takes time to make a numeric impact.
- Municipal and state agencies that accept public money should be mandated to provide basic human services.
- Provide housing for the homeless and in particular to populations such as prostitutes, runaways, and the undocumented at risk for HIV infection.
- Fund needle exchange and harm reduction at a level equal to drug-free and chemical-free treatment.
- Agencies should collaborate as partners, not competitors.
- Fund needle exchange programs.
- Ways to help: mental health outreach clinics; boys/girls community centers; sex clubs/sex workers; substance abuse; needle exchange. Take a good look at funding distribution.

**5. What are your recommendations on ways HHS can enhance HIV/AIDS care and treatment for your community?**

- Clinical trials at pt. clinic.
- Get information to the people.
- Increase funding for staffing and make treatment accessible to adolescents.
- More funding.
- More forums more often to address critical emerging issues.
- Bring PWAs and CBO workers into decision-making forums.
- Increase funding for testing and counseling.
- Insure money goes where it is needed.
- Make [care] available in languages other than English and work with community-based organizations to promote treatment. Many CBOs don't have enough funding for a treatment specialist.
- Expand ADAP funding.
- Create more partnerships between primary-care providers and community-based social service providers who assist in maintaining clients in care.
- More funding. More services.
- More E7 services. More needle exchange in New Jersey.
- Provide in-services for all service providers. The would mean more funding.
- Money for housing. Services for affected, not only affected.
- More community health clinics specific to HIV/AIDS cases should be set up and be readily available to adolescent communities.
- Require and provide technical assistance for partnerships among providers.
- Require needle exchange and harm reduction for entities in federal, state, and other public agencies.
- Require housing for the homeless and treatment on demand.
- Break down barriers. Fund dry treatment, mental health, correctional health, and tertiary-care facilities.
- Provide trials and medication in the communities. More funding for staff support. Advertise in the communities. Do research into the religious communities for assistance.
- Continue to ensure that Planning Councils are representative of communities and educate while orienting individuals concerning these processes. Equip them to do self-



advocacy in these forums.

- Break access-to-service barriers on HIV/AIDS in the Chinese population by creating more culturally and language appropriate programs, rather than denial of problems.
- Integrate alternative treatments. Possibly, the new incidence of diabetes could be circulated.
- Ensure funds meet epidemics. The city agencies are not sufficient.
- More education and awareness to the misinformed. More counseling available in a safe setting.
- Make funds available for housing and health care and AIDS-specific agencies for patients who choose hospitals. Do this either through changes in Medicaid, Medicare, and/or Ryan White.

**6. What are your recommendations on ways HHS can strengthen HIV/AIDS research for your community?**

- Clinical trials at pt. clinics.
- Conduct more research with women and people of color.
- Open more protocols and find more sites.
- Include people over 50 in all clinical trials. Reach out to older communities to see how devastated they are by the epidemic.
- Include 50-plus and older individuals.
- Bring more research into communities of color.
- Enhance the reward for trial patients.
- Work with CBOs to do research together.
- Provide a greater number of and access to clinical trials for children.
- Fund demo projects that research which types of intervention are most successful in assuring access and retention of substance users in care.
- Provide information to the community on surveys—i.e., public info, media info, etc.
- Conduct an updated study for incarcerated population in New Jersey.
- Provide research to the community in a way such that participants are well informed of the research conducted.
- Start with the premise, "Every life is worth saving." Stop pandering to corporate drug interests. Insure a pursuit of happiness for everyone or no one.
- Facilitate partnerships between CBO educational institutions and researchers. Encourage advisory boards of funded research.
- Fund research in effected communities. CBOs can do the research more cost effectively if we were to hire supervisory professional research staff in the hospitals and teaching facilities. Provide better access to those who need services.
- Increase operational expense funding for equipment, employee training. Provide training in agencies, and also to the Senate, Congressional and Presidential staff.
- Involve more people in training. Provide incentives for participation. Come to the communities.
- Create a research agenda designed on community desires rather than NIH goals, which may be different.
- Incorporate alternative treatments, i.e. herbs, vitamins, etc.
- Assist CBOs in Chinese communities. Needs assessment. Technical assistance sites. Produce hard data among this population.

**Additional comments:**

- Thank you!
- Stop playing politics with the media, the right, the American people, and the people of the world. Uncover Clinton, Whitman, and the RIGHT. Be brave. Stop making AIDS and human suffering a career ladder.
- Don't unite people to speak and then say the first person to the mike gets to speak only. That's rude.
- Rooms were too hot. Lunch mediocre. No where to set and eat lunch.
- It's a great location during the spring, summer, and fall.
- HHS is to be commended for holding this meeting. The voice of the community is absolutely necessary for any effective service to be provided.
- No snow next time. Need to have more bottled water supplied for people on medicine regimens.
- Two minutes is not enough time to make a point well.
- There is unfair practice of fund distribution between Brooklyn and New York City.
- More information regarding outcome of this community meeting and distribution of outcome evaluation/material related to information gathered.
- This meeting was very informative. More should be held as we advance towards the new millennium. We certainly should try.

## Appendix F

### FACT SHEET ON AIDS IN NEW YORK AND NEW JERSEY

**United States (Source: HIV/AIDS Surveillance Report, December 1998 Year-end Edition, Centers for Disease Control and Prevention)**

- In the US, a total of 688,200 persons have been reported with AIDS since the beginning of the epidemic. Between 1992 and 1997, the number of persons living with AIDS increased in all groups, as a result of the 1993 expanded AIDS case definition and more recently, improved survival.
- Nationally during 1998 (including the US possessions and territories), there were 48,269 reported cases of AIDS, as compared to 60,270 during 1997.
- Of all the reported AIDS cases nationally in 1998, more than half (57%) are located in the states of New York, California, Florida, Texas, and New Jersey. New York, with 8,714 reported AIDS cases in 1998 and an annual rate of 47.9 per 100,000 population, is the state with the largest number of AIDS cases in the nation; New Jersey ranks fifth with 2,134 reported AIDS cases and an annual rate of 26.3 per 100,000 population.

**New York State (Source: AIDS Surveillance Quarterly Update through December 1998, New York State Department of Health, Bureau of HIV/AIDS Epidemiology)**

- There were 131,411 cumulative number of AIDS cases reported in New York State through December 1998. Of these, 105,854 (80%) were located in New York City; 19,125 (15%) in upstate New York, and 6,432 (5%) in New York State prisons.
- The cumulative AIDS cases among adults in New York State including prison inmates is: 100,890 (78%) AIDS cases among males; and 28,388 (22%) AIDS cases among females.
- The racial and ethnic analysis of New York State cumulative adult AIDS cases reflects:  
53,303 (41%) African American,  
38,440 (30%) Hispanic,  
36,491 (28%) White,  
764 (<1%) Asian/Pacific Islander,  
63 (<1%) Native American, and  
217 (<1%) Unknown.
- The primary mode of transmission for adult males living with AIDS in New York State is:  
42,450 (42%) intravenous drug use,  
39,651 (39%) men who have sex with men,  
3,896 (4%) intravenous drug use/men who have sex with men,  
2,439 (3%) heterosexual contact,  
392 (<1%) hemophiliac,  
368 (<1%) blood transfusion, and  
11,694 (12%) unknown.
- The primary mode of transmission for adult females with AIDS in New York State is:



14,856 (52%) intravenous drug use,  
 8,882 (31%) heterosexual contact,  
 294 (1%) blood transfusion,  
 128 (<1%) hemophiliac, and  
 4,228 (15%) unknown.

**New York City, New York (Source: Estimates of Persons Living with AIDS in New York City, 1998 Edition, New York City Department of Health, Office of AIDS Surveillance)**

- New York is the city with the largest number of AIDS cases in the United States. There have been 110,897 cumulative AIDS cases reported through December 1998. Of these cases, 84,884 (77%) have been among adult males over 13 years of age and 24,100 (22%) have been among adult females over age 13.
- A cumulative total of 40,014 adults are living with AIDS in New York City: 29,900 (75%) males and 10,114 (25%) females.
- The primary mode of transmission among adult males living with AIDS in New York City is:
  - 12,242 (41%) intravenous drug use,
  - 11,255 (38%) men who have sex with men,
  - 1,605 (5%) probable heterosexual contact,
  - 1,195 (4%) heterosexual contact,
  - 154 (1%) blood transfusion, and
  - 3,415 (11%) unknown.
- The breakdown by race and ethnicity for the number of adult males living with AIDS in New York City is:
  - 11,333 (38%) African American,
  - 9,797 (33%) Hispanic,
  - 8,381 (28%) White,
  - 277 (1%) Asian/Pacific Islander,
  - 16 (<1%) Native American/Alaskan, and
  - 96 (<1%) Unknown.
- The primary mode of transmission for adult females living with AIDS in New York City is:
  - 4,569 (45%) intravenous drug use,
  - 3,264 (32%) heterosexual contact,
  - 748 (7%) probable heterosexual contact,
  - 118 (1%) blood transfusion, and
  - 1,390 (14%) unknown.
- The racial and ethnic breakdown for the adult females living with AIDS in New York City is:
  - 5,320 (53%) African American,
  - 3,488 (34%) Hispanic,
  - 1,239 (12%) White,
  - 36 (<1%) Asian/Pacific Islander,
  - 0 (0%) Native American/Alaskan, and
  - 31 (<1%) Unknown.

**New Jersey (Source: New Jersey HIV/AIDS Cases reported as of March 1999, New Jersey Department of Health and Senior Services, Bureau of HIV/AIDS Epidemiology)**

- There were 38,082 cumulative adult AIDS cases reported in New Jersey through March 1999. Of the state's 21 counties, Essex (11,333); Hudson (5,911), Passaic (3,236); Union (2,855);



and Middlesex (2,197) counties report the largest number of AIDS cases in New Jersey.

- Of New Jersey's cumulative AIDS cases, 27,464 (72%) have been reported among adult males and 10,618 (28%) have been reported among adult females.
- The racial and ethnic breakdown of New Jersey's cumulative AIDS cases among adults reflects:  
20,709 (55%) African American,  
10,405 (28%) White,  
6,065 (16%) Hispanic,  
127 (<1%) Asian/Pacific Islander, and  
71 (<2%) Unknown.
- The primary mode of transmission for adult males with AIDS in New Jersey is:  
12,848 (47%) intravenous drug use,  
7,718 (28%) men who have sex with men,  
1,551 (6%) heterosexual transmission,  
1,469 (5%) intravenous drug use/ men who have sex with men,  
224 (1%) blood transfusion,  
166 (1%) hemophiliac, and  
  
3,132 (12%) unknown.
- The primary mode of transmission for adult females with AIDS in New Jersey is:  
5,056 (49%) intravenous drug use,  
3,334 (32%) heterosexual transmission,  
238 (2%) blood transfusion,  
2 (<1%) hemophiliac, and  
1,639 (16%) unknown.





